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ABSTRACT

Seven issues (2002) of this organizational newsletter comprise the document. Issues typically include news items of interest to TASH members, conference information, and articles. Article topics include the following: public policy; book clubs for professional development; principles of sound research; research in support of advocacy; action research at the Center on Human Policy (New York); creating systems for communication and learning; augmentative and alternative communication systems; assistive technology and empowerment; understanding the abilities of people with autism; an interview with Donna Williams, an autistic woman; language acquisition; making friends within inclusive community recreation programs; opportunities for inclusion in leisure activities; using personal networks to achieve goals; customizing employment opportunities for people with disabilities; increasing consumer choice using Social Security work incentives; developing jobs in rural communities; application of universal design principles to education; "enabling" technology; assistive technology designed with the end user in mind; human centered technology and Section 508 and accessibility; and family support. (DB)

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TASH Connections

Volume 28, Issue No. 1\2, Jan-Feb 2002 – Issue No. 11/12, Nov-Dec 2002

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VOLUME 28 • ISSUE NUMBER 1/2 • JANUARY/FEBRUARY 2002

TASH CONNECTIONS

Equity, Quality and Social Justice for People with Disabilities

Inside This Issue

- 2002 Call for Presentations
- TASH Appoints National Development Coordinator
- 2001 Conference Highlights
- April 2002 Teleconferences on Autism
- Book Clubs for Professional Development: Using Disability Literature

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DON'T FORGET!

Upcoming Annual TASH Conference Dates

2002	Location:	Boston, Massachusetts
	Dates:	December 11, 2002 - Pre-Conference Workshops and Opening Reception
		December 12-14, 2002 - Annual TASH Conference
		Sheraton Boston and Hynes Convention Center
2003	Location:	Chicago, Illinois
	Dates:	December 10, 2003 - Pre-Conference Workshops and Opening Reception
		December 11-13, 2003 - Annual TASH Conference
		Chicago Hilton & Towers
2004	Location:	Reno, Nevada
	Dates:	November 17, 2004 - Pre-Conference Workshops and Opening Reception
		November 18-20, 2004 - Annual TASH Conference
		Reno Hilton & Towers

ITALY SEMINAR **Education in Italy: An Inclusive Approach**

May 14 - June 10, 2002 - Syracuse University

Why study inclusive education in Italy? United Nations observers cite Italy's programs as the most inclusive in the world. There are site visits to schools in Rome, Florence, Bologna, Parma, Frenza and a rural village near Naples; guest lecturers from local, regional, and national levels. Time is planned for enriching cultural experiences involving the history, art, and architecture in Rome, Florence, Venice, Parma, Pompeii, and Orvieto.

Write or call Dr. Carol Berrigan, Seminar Director, for more program information: Center on Human Policy, Syracuse University, 805 S. Crouse Avenue, Syracuse, N.Y. 13244-2280, (315) 443-3851, e-mail: crberrig@mailbox.syr.edu

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TASH Connections is available on audiocassette, in large print, and in Braille for people whose disabilities make these alternative formats preferable. Call (410) 828-8274 ext. 102 to request an alternative format.

Requests for permission to reprint material appearing in TASH Connections should be sent to: TASH Connections, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Priscilla Newton, Editor.

Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. **TASH** actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: **TASH**, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

TASH MISSION

TASH supports the inclusion and full participation of children and adults with disabilities in all aspects of their communities as determined by personalized visions of quality of life.

TASH's focus is on those people with disabilities who:

- Are most at risk for being excluded from the mainstream of society
- Are perceived by traditional service systems as being most challenging;
- Are most likely to have their rights abridged;
- Are most likely to be at risk for living, working, playing, and/or learning in segregated environments;
- Are least likely to have the tools and opportunities necessary to advocate on their own behalf;
- Historically have been labeled as having severe disabilities; and,
- Are most likely to need on-going, individualized supports in order to participate in inclusive communities and enjoy a quality of life similar to that available to all citizens.

TASH accomplishes this through:

- Creating opportunities for collaboration among families, self-advocates, professionals, policymakers and other advocates;
- Advocating for equity, opportunities, social justice, and rights;
- Disseminating knowledge and information;
- Supporting excellence in research that translates to excellence in practice;
- Promoting individualized, quality supports;
- Working toward the elimination of institutions, other congregate living settings, segregated schools/classrooms, sheltered work environments, and other segregated services and toward replacing these with quality, individualized, inclusive supports;
- Supporting legislation, litigation and public policy consistent with **TASH**'s mission; and,
- Promoting communities in which no one is segregated and everyone belongs.

WHOM DO I CONTACT?

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828- TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 2002 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on governmental affairs, call:** Jamie Ruppmann, Director of Governmental Relations, at (410) 828-TASH, Ext. 104, e-mail: jruppmann@tash.org
- **For information on newsletter submissions and advertising, marketing and promotions, or permission to reprint, call:** Priscilla Newton, Director of Marketing, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the Journal (JASH), call:** Fredda Brown, Editor-in-Chief, at (718) 997-5243, e-mail: fbrowncuny@aol.com
- **Don't forget to visit TASH's web site at http://www.tash.org**

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From the Executive Director
BY NANCY WEISS

What's new at TASH?

The annual conference is not only a time of learning, networking and excitement, it is also the time at which TASH's Executive Board holds its annual meeting. Here are some of the things that are new for TASH:

At the Anaheim Conference, Board members, committee chairs, chapter leaders and other interested TASH members came together for a half-day strategic planning session. The group discussed TASH's accomplishments, the organization's priorities for the coming year, how we would like people to view TASH in 3-5 years, and what needs to happen to accomplish these goals. This strategic planning session took the place of the regularly held Chapter Leadership Day. At this year's conference in Boston, the Chapter Leadership Day will again be scheduled for the Wednesday preceding the conference.

With the input of the Strategic Planning group, the Board adopted the following priorities for 2002.- The Board member taking responsibility for each is identified in parenthesis. If you have interest in working toward the accomplishment of any of these priorities, contact the board member identified for that activity (contact information is available on TASH's web site: www.tash.org or can be obtained by calling central office at 410-828-8274, ext. "0").

TASH's 2002 Priorities:

ADVOCACY RELATED PRIORITIES

O Collaborate/build support and connections with general educators (June Downing)

O Collaborate/build support and connections with other social justice organizations (Dick Sobsey)

O Work toward building community supports and closing institutions and other segregated living and work settings (Jeff Strully)

O Strengthen the voices of people labeled severely disabled (Doug Biklen)

O Promote the participation of people with disabilities in post-secondary education (Barbara Ransom and Patrick Schwarz)

O Promote the reauthorization of the Individuals with Disabilities Education Act (IDEA) in a manner consistent with TASH's mission (Kathy Gee and Lu Zeph)

O Increase the participation of minorities within TASH (Wanda Blanchett and Donna Gilles)

O Promote participation of young children in inclusive early care and education settings (Lu Zeph)

O Promote implementation of positive behavioral supports and elimination on the use of aversive, coercive and restrictive procedures and the inappropriate use of restraints (Jacki Anderson and Fredda Brown)

OPERATIONS RELATED PRIORITIES

O Assure committees have the support they need (all Board members in their roles as committee liaisons)

O Assure chapters have the support they need (Donna Gilles)

O Increase membership (all)

O Fiscal development (Jorge Pineda and Wanda Blanchett)

O Conduct effective legislative advocacy (Kathy Gee)

New Regarding TASH Committees: At their meeting in Anaheim, the board approved the establishment of two new committees, a Committee on Post-Secondary Education, co-chaired by Caren Sax and Carol Tashie, and a Committee on Spirituality, co-chaired by Maureen Keyes and Kathy O'Connell. TASH also re-established its Media Operating Committee. This committee will be chaired by Board member, Marcie Roth.

Some changes were made with regard to Board liaisons for committees. See the grid on page 5. All TASH members are invited to participate in all committees. If you have interest in the work of a particular committee, contact the committee chair or liaison. See TASH's website at www.tash.org for contact information, or call the central office at 410-828-8274, ext. "0".

TASH has a New National Development Coordinator: TASH has contracted with Jim Peters to serve as National Development Coordinator. Jim is a great supporter of TASH's work, the parent of a son who has a disability, and an effective spokesperson for progressive disability policy and supports. Jim will work on fundraising, promoting TASH membership, and, in conjunction with Jamie Ruppmann, TASH's Director of Governmental Affairs, assisting in efforts to influence state and Federal policy (see photos of Jim in his new role beginning on page 8).

Continued on page 5

What's new at TASH?

Continued from page 4

TASH Committee Contacts

Operating Committee:	Chair(s)	Board Liaison
Alice H. Hayden	Beverly Rainforth	Kathy Gee
Chapter	Donna Gilles and Linda Rammler	Donna Gilles
Conference Planning	Doug Biklen and Lou Brown	Doug Biklen
Development	Wanda Blanchett	Wanda Blanchett
Elections	Lou Brown and Patrick Schwarz	Patrick Schwarz
Executive	Jacki Anderson	N/A
Finance	Jorge Pineda	Jorge Pineda
Governmental Affairs	Kathy Gee	Lu Zeph
Media	Marcie Roth	Marcie Roth
Membership	Liz Obermayer	Liz Obermayer
Personnel	Jeff Strully	Jeff Strully
Publications	Jacki Anderson	Kathy Gee

Committee:	Chair(s)	Board Liaison
Communication Issues	Don Cardinal	Doug Biklen
Community Living	Patti Scott and Joe Wykowski	Jeff Strully
Criminal Justice Issues	Barbara Ransom	Dick Sobsey
Early Childhood	Elizabeth Erwin	Lu Zeph
Education	Michael McSheehan and Mara Sapon-Shevin	Kathy Gee
Employment and Transition	John Butterworth and Mike Callahan	Liz Obermayer
Guardianship Alternatives	Mayer Shevin	Dick Sobsey
Individuals with Special Health Care Needs	Jill Greene and Donna Lehr	Fredda Brown
International Issues	Zuhy Sayeed and Anne Smith	John Lian
Leisure and Recreation	Cynthia Burkhour	John Lian
Multicultural Issues	Lynda Baumgardner and Susie Schaefer	Jorge Pineda
Paraeducator Issues	Pat Mueller	Patrick Schwarz
Peace	Craig Michaels	John Lian
Personnel Preparation	Lewis Jackson	June Downing
Positive Behavioral Approaches	Tim Knoster and Rob O'Neill	Jacki Anderson
Post Secondary Education	Caren Sax and Carol Tashie	Patrick Schwarz
Related Services	Bev Rainforth	June Downing
Sexuality	Dave Lenox	Wanda Blanchett
Spirituality	Maureen Keyes and Kathy O'Connell and	Patrick Schwarz

Are you interested in submitting an article for publication in TASH *Connections*? Upcoming topic areas include: Inclusive Child Care, After-School, and Summer Recreational Programs; Positive Behavior Supports; Autism; Special Health Care Needs; Literacy; and Over-identification/ Over-representation of Minority Students in Special Education.

If you would like to submit an article for consideration, please send an e-mail to Priscilla Newton, Editor, TASH *Connections* at <pnewton@tash.org>

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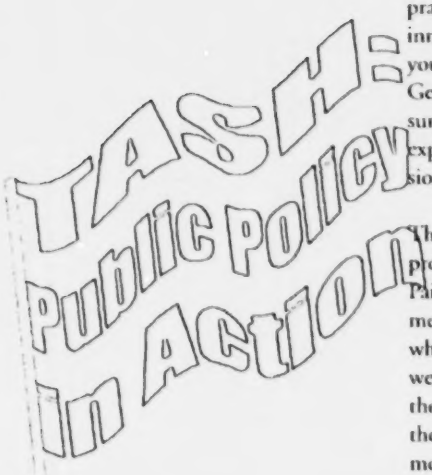

TASH REPRESENTATIVE ADDRESSES PRESIDENT'S COMMISSION

The President's Commission on Excellence in Special Education held an organizing meeting January 15, 2002 and set their agenda for the next four months. Members met for an all-day planning session, which included a welcome address from Rod Paige, U.S. Secretary of Education, and the formation of Work Groups to study issues regarding accountability, assessment systems, personnel preparation, research, finance systems, and outcomes.

Jamie Ruppmann, Director of Governmental Relations, was one of twelve citizens given an opportunity to speak informally to the Commission at the end of this first full meeting.

"There are Washington-based pundits and policy makers who have asserted that people with disabilities and their families do not think 'outside the box' and are resistant to efforts to make IDEA excellent and accountable. They are wrong." Jamie said.

She went on to assure the Commission members that, "in fact, self-advocates and parents will be one of your best sources of information about the efficacy of current practices and the strongest supporters of innovation. Our support will be critical to your success," she concluded.
Generally, advocates were pleasantly surprised by the comments and concerns expressed by the Secretary and the Commissioners.

"The President " is committed to the bold proposition that every child can learn," Paige told the commission. "This doesn't mean that, after you siphon off the children who have disabilities; or the children who were never properly taught how to read; or the children who never learned English; or the children who disrupted their classrooms, most of the rest of them can learn."

"It means that all of our kids, even the ones our system calls 'hard to teach' can learn. This means that even students with disabilities can learn to high standards."

Paige also called on the commission to discover what works to improve the performance of students with disabilities.

"Your task as a commission is to discover what works to improve the performance of students with disabilities receiving special education," he said. "Talk to other experts. Examine research. Study preventive reading programs, and tell us how Washington can help state and local communities provide excellent special education services."

President Bush created the commission in October to collect information and study issues related to Federal, state and local special education programs with the goal of recommending policies for improving the educational performance of students with disabilities.

The commission is charged with producing a final report to the President by this summer that contains findings and recommendations in the following nine areas:

1. Cost-effectiveness: The effectiveness and cost of special education and the appropriate role of the Federal government in special education programming and funding, including an analysis of the factors that have contributed to the growth in costs of special education since the enactment of the Education for All Handicapped Children Act (a predecessor of IDEA);

2. Improving Results: How federal resources can best be used to improve educational results for students with disabilities;

3. Research: A special education research agenda;

4. Early Intervention: The impact of providing appropriate early intervention in reading instruction on the referral and identification of children for special education;

5. Funding Formulae: The effect of special education funding on decisions to serve, place, or refer children for special education services and possible alternative funding formulae that might distribute funds to achieve better results and eliminate any current incentives that undermine the goals of ensuring high-quality education for children with disabilities;

6. Teacher Quality and Student Accountability: How the Federal government can help states and local education agencies provide a high-quality education to students with disabilities, including the recruitment and retention of qualified personnel and the inclusion of children with disabilities in performance and accountability systems;

7. Regulations and Red Tape: The impact of federal and state statutory, regulatory and administrative requirements on the cost and effectiveness of special education services, and how these requirements support or hinder the educational achievement of students with disabilities;

8. What Models Work in the States: How differences in local education agency size, location, demographics and wealth, and in-state law and practice affect which children are referred to special education and the cost of special education; and

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TASH Public Policy in Action

Continued from page 6

9. Federal v. Local Funding: A review of the experiences of state and local governments in financing special education, and an analysis of whether changes to the federal "supplement not supplant" and "maintenance of effort" requirements are appropriate.

Commission members approved the following meeting schedule:

February 25-27, Houston, Texas
March 6, Denver, Colo.
March 13, Des Moines, Iowa
March 20, San Diego, Calif.
March 21, Los Angeles, Calif.
April 9-10, Miami, Fla.
April 16, New York City, N.Y.
April 18, Nashville, Tenn.
May 30-31, Washington, D.C.

The purpose of these meetings is to hear from experts and members of the public who will provide the commission with information and guidance. More information about the President's Commission is available on the TASH website at www.tash.org

TASH URGES "ADEQUACY OF INCENTIVES" STUDY OF TICKET TO WORK

Concerned and disappointed that the newly implemented Ticket to Work payment strategies provided by the Social Security Administation do not meet the needs of people with significant support needs, TASH has urged the Ticket to Work Panel to immediately implement the Adequacy of Incentives study required by Congress in the legislation and, most important, to use employment researchers and field-based experts in the area of employment design and supports to inform the study.

In recent testimony to the Ticket to Work and Work Incentives Improvement Act (TWWIIA) Panel, TASH reminded panel members that "individuals with disabilities and their families mobilized an intensive national effort to convince Congress to approve the equity (AOI) language with the intent that individuals with significant disabilities should have the chance to use the ticket. This panel has heard excellent recommendations from top experts in the field, backed by public comment. There should be no further delay in moving forward with strong recommendations based on the work of the Experts Rountable."

Attention TASH Members!

The Paraeducator Interest Group is seeking contact information from members who are interested in issues related to the employment, deployment, training and support needs of paraeducators.

If you are interested in issues related to paraeducators, please send an e-mail to Nancy Weiss at the TASH central office <nweiss@tash.org> expressing your desire to be a member of the Paraeducator Interest Group. We will send respondents a copy of the TASH Resolution on Paraeducators, build a resource network and communicate relevant information to you.

ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of JASH for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this:

Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year — in addition to an extra full year's worth of journals!

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To receive materials or to learn more about TASH's Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

TASH Appoints National Development Coordinator

If there is doubt in anybody's mind that TASH is committed to, and strives to be the driving force for quality and social justice for individuals with disabilities, then just look at the new position of National Development Coordinator for TASH and the mission I will pursue.

You may be asking, "What does a National Development Coordinator do?" "How will this new position affect me, my child?" "Will it help friends and family support those with disabilities?" "What impact will this new position have on me as an educator, a parent, an advocate, a care provider, a person with disabilities?" No one is more skeptical of bureaucracy than I, so let me tell you a little about myself to acquaint you with the man who holds this new position.

For over 14 years, I have been persuading school districts and public agencies to provide quality services, training, and support so that every individual with any disability can live an inclusive and productive life. I have been mobilizing parents to become the driving force for inclusive education in their local schools. I have been reminding teachers, group home care providers, supported living vendors, and vocational program job coaches that self-determination is not a request made by individuals with disabilities or their families. It is, in fact, a right under the U.S. Constitution.

I am offended by those who say people with special needs just want a "disability check" when what we really want is to earn a steady pay check. I demand that children and adults with disabilities receive positive behavioral supports and stop being restrained sometimes to the point of death.

A Message from

Jim Peters,
TASH National Development Coordinator

"For some of you who say this is <u>like</u> a civil rights movement, I want you to realize that this <u>is</u> a civil rights movement."

For those who are unaware of our casualties of war, I want to tell you of a 15- year-old who died after being put in a restraining hold for 11 minutes; the 11-year-old, weighing 96 pounds, who was crushed to death when two aides sat on his back because he refused to move to another table; the 6-year-old who died of asphyxiation after being strapped to his wheelchair and left unattended; the child who died after worker at his home wrapped his body in a blanket, rolled him up in a mattress bound together by leather straps, and left him for four hours; and the 15-year-old who suffocated while being held face-down after resisting an aide who instructed her to hand over a family photograph. There are many more of these stories that continue to happen.

For some of you who say this is like a civil rights movement, I want you to realize this is a civil rights movement.

I have a 14-year-old son who has autism. I live and understand the feelings and struggles of the millions of Americans who have disabilities, have family members with disabilities, or are affected by disability laws. I have taught Special Education Law at California New Hope University, and I communicate regularly with members of Congress on both sides of the aisle.

Some say I am an agitator because I support the concept of self-determination for individuals with disabilities — because I can imagine a future where individuals with disabilities are included as valuable members of the community — because I urge people with disabilities and their families to fight for the human dignity, companionship, and community that should have been ours from birth. Some will call us agitators whenever we stand up for what is just; I can assure you, I will continue to do just that - I will never move from what is right!

As TASH's new National Development Coordinator, my mission will include:

1) improving and expanding fund raising by seeking individual, corporate, and foundation donations, and organizing national fund raisers;

2) marketing and promoting TASH membership by meeting with individuals, parent groups, and other related groups to increase awareness about TASH and disseminating research and resource information to parents and advocates;

3) serving as a spokesperson for TASH in State and Federal policy efforts with the goal of promoting progressive disability policy and increasing staff and legislator recognition of TASH as representative of the needs of individuals with disabilities.

I am going to raise funds to implement the following programs:

❖ free legal information to members of TASH through an 800 number and referral to qualified advocates and attorneys;

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TASH Appoints National Development Coordinator

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"I am asking today that every person send $50.00 to kick off our Million Dollar Drive."

❖ referral of TASH members to parent groups, self-advocacy groups, professionals and services to assist in their local area;

❖ instructional information on how to obtain an inclusive education;

❖ inform and convince Federal legislators to keep and improve IDEA and ADA, as well as State legislation to enforce the laws that continue to be circumvented;

❖ protect those who lack the capacity or the assistance to stay out of jails and institutions.

My goal is to raise one million dollars to implement these programs. Our team will come to every state to set up fundraising events, disseminate research findings, membership information, and gather information to deliver to our State and Federal legislators about what is really going on in our communities. We will need your help. If you call, we will call you back. If there is information you need or want to share, please call, write, or send us an e-mail.

I am asking today that every person send $50.00 to kick off our million dollar drive. Please fill out the form to the left and mail it to:

TASH Million Dollar Drive
29 W. Susquehanna Avenue
Suite 210
Baltimore, MD 21204
or call in your donation to:
1-800-482-8274, ext. 109
E-mail: jpeters@tash.org

You can also make your donation online. Visit TASH's web site at www.tash.org and follow the link to the Million Dollar Drive page.

Join us in our campaign to build the awareness, knowledge, and funds that are needed to make change happen.

TASH MILLION DOLLAR DRIVE

Name _____

Address _____

_____

Telephone ( ) _____ *E-mail* _____

❒ *MasterCard* ❒ *Visa* ❒ *Discover*

Card # _____ *Exp. Date* _____

Signature _____

Donation of $ _____ *enclosed*

Make checks payable to: ***TASH Million Dollar Drive*** *and mail with this coupon to: TASH Million Dollar Drive, 29 W. Susquehanna Avenue, Suite 210, Baltimore, Maryland 21204.*

❒ *$50.00* ❒ *$75.00* ❒ *$100.00* ❒ *Other*

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TASH Appoints National Development Coordinator

Continued from page 9

Excerpts from Jim Peters' Keynote Speech at the 2001 Annual TASH Conference

We did not lack patriotism when we called on Washington and Congress to pass IDEA and the Americans with Disabilities Act. When I testified before Congress during the reauthorization of IDEA, our leaders in Washington told me in this land of the free and home of the brave, all Americans have a right to inclusion, freedom, self-determination, justice, and equal treatment under the laws of this country.

Now I say, enforce those laws. Make them live for us and for those whom we love.

Enforce those laws until every child with special need is given the opportunity to be included. Enforce the laws until every public building is accessible. Enforce the laws so grown men and women with disabilities are not treated like children. Enforce the laws they tell us are already on paper.

There are flaws in the way individuals with disabilities are treated, taught, and assisted. We must take it upon ourselves to bring about the change that is so vital so that all people, Black and White, Jew and Gentile, Asian and Hispanic, Muslim and Arab, Protestant and Catholic can live in an inclusive, self-determined, equitable society where social justice is never in question.

"...all Americans have a right to inclusion, freedom, self-determination, justice, and equal treatment under the laws of this country."

We must help each other and push for more research together ... go to school board meetings together ... talk to our legislators together ... walk together ... go to court together ... go to Washington together ... and we've got to stop the practice of excessive restraints together. We fall down sometimes, we trip up sometimes, we get knocked down sometimes, but we must get back up."

Jim Peters and TASH Governmental Affairs Director Jamie Ruppmann (r) present an award to Virginia Congressman Bobby Scott in recognition of his service to children, youth and adults with disabilities and their families.

TASH also recognized the efforts of Colorado Congresswoman Diana DeGette (center) for her support of health care services for children and families.

A Look Back at the 2001 TASH Conference

TASH's 2001 Conference, "*Imaging the Future,*" was a celebration of sharing, learning and unity of spirit. Over 1400 people from across the United States and from several countries attended the conference and enjoyed Disneyland and the warmth of the California sun! Attendance was a bit lower than expected as the events of September 11th had a profound effect on everyone. Some of our speakers and attendees made the decision not to attend the conference this year due to a variety of personal reasons ranging from the desire to stay near family to organization-imposed travel restrictions. While we missed those who could not be with us, we certainly understood and respected the reasons for their absence. Many more presenters and members decided to press on with their plans to join us in Anaheim, and to those we are thankful.

A review of the conference evaluations shows that attendees enjoyed the more than 400 breakout sessions facilitated by quality speakers. It was noted that the program offered a more balanced variety of session topics than in previous years. Participants were pleased with the overall registration process and they found the volunteers and staff to be very helpful and friendly. Many participants commented on the excellent customer service provided by the Anaheim Marriott. There was a nearly unanimous feeling among conference attendees that the hotel staff was friendly, welcoming, respectful and communicated a sincere desire to make our visit at the hotel a great one — and they succeeded! Other conference highlights reported by our attendees were:

- great networking opportunities at the poster sessions, roundtable luncheons and receptions
- fun location and functional facility
- well organized logistics for the conference
- great exhibitors

Conference attendees also offered some great suggestions for future TASH conferences:

- More exclusive exhibit time
- Feature a Panel of Experts with a time and location to meet them
- Make copies of keynote speeches available
- Have a highlight/overview of each day's special events and keynote speakers on inside or outside cover of the conference program
- A place for attendees to connect (i.e. a designated time and area to meet)
- A flyer listing accessible transportation options and nearby accessible and affordable dining
- Stop preaching to the choir, piggy back onto other conferences to bring "outsiders" in
- More prominent request for self-advocates as presenters

Many thanks to the conference committee, the proposal review board, the strand coordinators, the presenters, the local committee, the exhibitors, the sponsors, the TASH board and staff, and all of the attendees who make this incredible event such a wonderful success. Your efforts and energy sustain many folks throughout the year in their struggles for inclusion and equity for all.

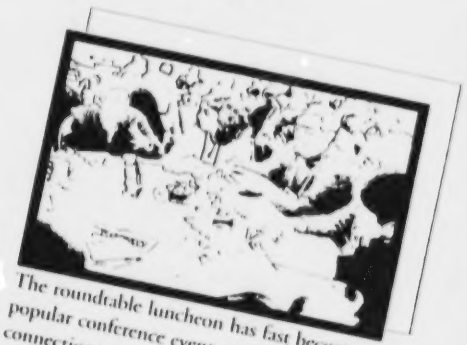
2001 Conference Highlights

2001 TASH Conference
Anaheim, California

Although attendance was lower than expected due to the tragic events of September 11th...

TASH exhibitor and Images Award recipient Beth Mount (center) share insights about her work.

June Downing, president of Cal-TASH, helped welcome TASH attendees to the first annual meeting in California since 1995.



The roundtable luncheon has fast become a popular conference event at which to make connections and share information.

Lively entertainment was provided in the Exhibit Hall during Friday evening's reception and raffle/auction.

Opening reception guest speaker Laura San Giacomo (seated) was available after the event for discussions and photos.

Nancy Weiss, left, presents a 2001 Images Award to representatives of Cingular Wireless at Thursday evening's Images Award Reception. TASH Board Member Marcie Roth, rear, served as the program Mistress of Ceremonies.

Saturday morning poster sessions in the Exhibit Hall offer a unique and intimate forum at which speakers can share their presentations with attendees.

...the TASH Conference continues to be a unique cross-disability event at which attendees come away re-energized, re-connected, and re-committed!

"No one should have to struggle so fervently for the simple right to be educated. But for a long time I lacked the proper supports to succeed. ...I believe deafblind people, or any person with special needs, can do anything if they have the right kind of supports."

Excerpts from Keynote Address by Corrina and Pearl Vessart

Pearl Veesart

I was driving a stretch of Highway 1, when my daughter, then about 9 or 10 years old, said "Mom, did you want a deafblind child?" Corrina is deafblind. In true "kid-form" her penetrating question came when I was indisposed. I need my hands to communicate with her, and they were on the steering wheel. I can only give short, one-word, or brief answers when I'm driving...yes, no... I thought to myself, "no", I didn't "wish" for a deafblind child. The idea never entered my mind! She was waiting for an answer. I signed "no," pained with the too-limited, constrained response. After a thoughtful moment, she asked, "Then why did you get one?" Again, I needed a short, one-word answer. I signed "lucky" and the exchange ended there.

I see deafblind as a way-of-life. An interesting culture with language, customs, its own issues, and way to function. In a world often starved for human connectedness and touch, the "deafblind way" can offer a type of closeness and intimacy most people never know, and some cannot handle.

That said, I realized early on, whatever capabilities and attitudes I have as a mother within my own home, could take Corrina only so far. She needed (and needs) a place in the world. The crucial key being a good education. The majority of the past twenty years I've been seeped in IEP's, meetings, and agendas. I've learned to make-a-case, prove-a-point, and get-the-service. It's a technical, facts-only, time-is-short, people-are-busy existence. It's not about feelings; it's about needs. I've gotten good at that, and grown comfortable there with twenty years of unrelenting practice.

In the 1930's Helen Keller made tremendous headway in gaining rights and recognition for people with special needs. Here we are in 2001, seven decades later, and it's taken more than I can describe here to procure that free and appropriate public education (FAPE) Corrina so richly deserves. I will say briefly, what worked for me, was to learn the laws (read the education code), get expert input and participation, and be prepared to make a stand. It makes a difference!

When Corrina was young she would ask me repeatedly if she were a "real person." I realized she felt so disconnected in school ("like a statue") that she truly questioned her being. One day I took her to a children's African dance class. It was on a wooden floor, with powerful live drummers. After sitting for quite some time she rose and began to dance herself. She danced on her own, in perfect synch with the music. Corrina came to me and queried "Mom, is this real?" " Yes," I said. This time, she was so connected, it felt unreal! When class ended the teacher walked over to me and exclaimed, "she's a beautiful dancer." The woman knew nothing of Corrina being deafblind. I said with tears streaming "she's never danced before."

And now, I give you, Corrina Veesart -- a real person.

Corrina Veesart

"Hello! My mother will be reading a poem in a few minutes, which I wrote my junior year in high school, and is very relevant to my life experiences. I thought I'd share it with all of you.

It's taken a lot of persistence and openness for me to learn. It's been a hurdle; I've had to struggle to conquer. No one should have to struggle so fervently for the simple right to be educated. But for a long time I lacked the proper supports to succeed. No one seemed willing to accept my needs or to provide consistent access to sign language, interpreters, Braille, and other important things that made learning possible for me. But through the support of my faithful mother, friends, a few available teachers, I've fought feverishly for my right to an education, twice having to go to fair hearings.

Over time things slowly began to change, and my world expanded as reinforcements and new adaptations began to enter my life. After years of being locked away, furiously banging at the closed doors of freedom, new interests and opportunities began to develop for me. I came to love music through feeling its vibrations, to study dance, and even become a high school cheerleader.

These things have helped me to open up, to grow to meet new friends and to become somebody with a goal, [somebody] who can be successful. I believe deafblind people, or any person with special needs can do anything if they have the right kind of supports.

If the things you want in life are not readily guaranteed, then fight for them with all your might and all your heart, until your dreams are no longer denied and the future is yours!"

Teacher and Me

By Corrina Veesart

In the days of dolls and toys
It was Teacher and Me
Blocks upon the table
Using fingers to mold a model.

Touch, smell, taste, sight, and sound
Enlightening me.

Behavior forming inside.
It was misty and unclear.
Teacher was strict
I must do it the "right" way...not the "hard" way.

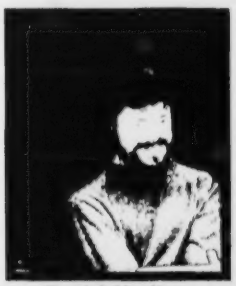
Continued on page 19

2001 Conference Keynote Presenters

Caroline "Annie" Thomas and friend

John Thomas Sanford, III

Corrina Veesart



Daniel Keplinger

Pearl Veesart

Tari Susan Hartman

Jim Peters

and Congratulations! to the TASH Award Winners

Kathryn D. Peckham-Hardin, recipient of the 2001 ***Alice H. Hayden Award*** for Demonstrated Potential in Leadership, Teaching, Scholarship and Service on Behalf of People with Disabilities

Leslie C. Soodak and **Elizabeth J. Erwin**, recipients of the 2001 ***Thomas G. Haring Award for Excellence in Research*** for the quality and significance of their article, *"Valued Member or Tolerated Participant: Parents' Experiences in Inclusive Early Childhood Settings,"* JASH, Volume 25(1)

Our Quest: Opportunity, Equality, Justice

2002 TASH International Conference
December 11-14th
Sheraton Boston and Hynes Convention Center

Co-Sponsored by: TASH NEW ENGLAND **Chapter**

Call for Presentations

All people, regardless of their label or perceived level of disability, should have the supports they need to direct the course of their own lives, and to live and participate successfully in the community.
All means All!

The 2002 TASH Conference Committee strongly encourages presentations that demonstrate "how-to" strategies, present research, or tell stories about changes in images, attitudes and systems that have empowered individuals with disabilities who have traditionally been denied access to reach their dreams and goals.

Proposals should be submitted on topics that demonstrate innovation, collaboration, energy and daring. When possible, presentations should be made by a team that includes individuals with disabilities, family members, advocates, and professionals.

1) *If accepted to present, All* presenters are required to pay conference registration fees.
TASH relies on membership and conference registration to be an independent and powerful advocacy organization. We strongly encourage presenters to be TASH members. International TASH members, self-advocates, parents, and family members are eligible to register at a reduced rate.

2) A description or abstract of the proposed session must be sent along with the completed application, postmarked by March 29, 2002.
Abstracts need to contain the following information: (1) describe the topic or issue addressed, (2) describe the importance and contributions of the session, (3) describe how the proposal meets current or emerging standards for "best practice," (4) describe the session format - i.e. skill-building, program discussion, panel, etc.

3) Proposal content must reflect the values and resolutions of TASH.
TASH is dedicated to disseminating information that reflects the realities of pursuing equity, social justice, diversity, and full school, community, and work inclusion for people labeled with disabilities, particularly those who are at most risk of being excluded from community life. The proposal title, description, and all content of presentations must use "people first" language, and must support the value of inclusion. **Presenters need to ensure that materials for the session are accessible to a broad range of ability levels, and are made available in alternative format, such as computer text files or large print.**

4) Please limit the abstract to 300-600 words (1 - 1 1/2 pages).
Do not send any other materials. You may submit the information on the application form or in alternate format, as long as all of the information requested is included. The form is available to download from TASH's web page: www.tash.org. You must, however, print and mail the form as per the guidelines. Please **DO NOT** email your proposal, as we cannot assure receipt of electronic transmissions.

5) Proposals are cross-rated by three reviewers on the following criteria:
1) relevance to TASH mission
2) interest to TASH members
3) extent to which information is state-of-the-art or cutting-edge
4) the practicality of content
5) the clarity of the proposal

Each session chairperson will receive notification in July regarding the status of his/her submission.

TASH

The 2002 TASH Call for Presentations is available in alternate format upon request.

29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 ❖ www.tash.org ❖ 410-828-8274

2002 TASH Conference Presentation Application

Please complete all sections of this form. Submit 4 copies of the form and 4 copies of the required attachments listed below. ***Mail by March 29, 2002 to:***

Kelly Nelson, TASH, 29 West Susquehanna Avenue, Suite 210, Baltimore, MD 21204
Questions? Phone: 410-828-8274 x 105
Sorry, faxed or e-mailed copies cannot be accepted.

Date Received: _____

Session Code: _____

Coordinator (You may only submit as a session coordinator on **one** proposal) :

_____

ORGANIZATION : _____

ADDRESS: _____ CITY: _____

STATE/PROVINCE: _____ COUNTRY: _____ ZIP/POSTAL CODE: _____

DAYTIME PHONE: _____ HOME PHONE: _____

FAX: _____ E-MAIL: _____

The above address is: ❒ HOME ❒ WORK ❒ OTHER _____

Session Information *Please attach an abstract which includes the following information:*

- Session Title
- A short (40 word) description of your session that will be used in the conference program. *Participants will select which session to attend based on this description, so write the description with care!*
- An abstract [not to exceed 600 words (1 1/2 pages)] that describes: the topic, how the presentation meets current or emerging standards for "best practice," and the session format.
- A listing of all co-presenters, with contact information including: name, address, phone, fax, and e-mail for each person.

Requested Session Type:

(Please check only one)

❒ Performance/Art Display
❒ Roundtable Luncheon Discussion
❒ Poster Session
❒ 1 Hour Breakout Session
❒ 2 Hour & 15 minute Breakout Session

❒ **I understand that it is my responsibility to contact co-presenters regarding their participation in this session and to inform them of the requirements listed on the guidelines for submission (including payment of conference registration fees) if accepted.**

Signature *(required)*: _____

Applicable Interest Area *(This category determines which committee reviews your proposal. Please pick only one)*

❒ ADVOCACY
❒ AGING
❒ ASSISTIVE TECHNOLOGY
❒ CREATIVE/PERFORMING ARTS
❒ COMMUNICATION
❒ COMMUNITY LIVING/HOUSING
❒ CRIMINAL JUSTICE
❒ INCLUSIVE EDUCATION
❒ URBAN EDUCATION
❒ HIGH SCHOOL INCLUSION
❒ INTERNATIONAL INCLUSION
❒ STATEWIDE ALTERNATE ASSESSMENT
❒ EARLY CHILDHOOD
❒ EMPLOYMENT
❒ ETHICS/RIGHTS
❒ FAMILY
❒ GUARDIANSHIP ALTERNATIVES
❒ GOVERNMENTAL AFFAIRS
❒ LEISURE AND RECREATION
❒ LITERACY
❒ MANAGEMENT ISSUES
❒ MULTICULTURAL
❒ PARAPROFESSIONAL
❒ PERSONNEL PREPARATION
❒ POSITIVE BEHAVIORAL APPROACHES
❒ RELATED SERVICES
❒ RESEARCH
❒ SELF-DETERMINATION
❒ SPECIAL HEALTH CARE NEEDS
❒ SPIRITUALITY
❒ SEXUALITY/ SEXUAL EXPRESSION
❒ STUDENTS WHO "SEVERELY" CHALLENGE SCHOOLS BUT WHO DO NOT HAVE LABELS OF "SEVERE" DISABILITIES
❒ TRANSITION

Other related interest areas to which this session would apply:

_____

_____

TASH's work is dependent on the financial assistance of our donors and members. We wish to acknowledge the generous support of our newest lifetime member

Mark Partin ~ Middlefield, Connecticut

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments.

If you are interested in becoming a lifetime member of TASH, please contact Rose Holsey at 410-828-8274, ext. 100.

◆◆◆◆◆

Thanks, too, to the gracious donations of the following individuals and organizations:

Jacki L. Anderson
Christine Bevilacqua
Wanda J. Blanchett
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AN INTERVIEW WITH MICHELLE ON BEING BEN'S SISTER

BY TERRY BOISOT

Last November at the annual TASH conference in Anaheim, California, my fifteen-year-old daughter, Michelle, received the Cal-TASH "Mary Falvey Outstanding Young Person Award" for her leadership in the field of inclusion of people with disabilities. The award nomination was made by Dr. June Downing, President of Cal-TASH, and came as a complete surprise to Michelle. She is so humble about her accomplishments, and is kind of a quiet force that has great influence in changing attitudes and direction of the lives whose paths she crosses -- including her brother's and mine.

The following interview was hard for Michelle, and she struggled with finding the right words. Her life is such a profound example of inclusion and acceptance, and she doesn't realize how important her life's example is. Everyday she lives and breathes what most of us took many years to discover. The world is in good hands with Michelle.

Q: When you think of your brother, what comes to mind?

A: That's a good question. I think he has a really good influence on me. In general, I think of how much Ben has probably influenced the way I treat other people, and he has helped me understand what is important in life. He judges no one. He doesn't care what people wear or what they look like. He has given me the ability to feel good about myself, and not feel pressured by peers to be something I'm not. I don't like when the "cool" kids judge other kids because their clothes aren't fashionable, they look different, or their hair isn't stylish. I will never be one of the "cool" kids because they are not so cool anyway.

Q: Is it hard being Ben's sister?

A: Sometimes. It's hard when my brother and I are in say, a Blockbuster, and I run into someone from school that doesn't know I have a brother with disabilities. People don't always know what to say to Ben and me. So, to avoid those uncomfortable situations, I do what I can to lay the groundwork by making Ben the subject of my reports at school, I tell people in advance that I have a brother with disabilities and I love him a lot, and I plan Abilities Awareness events so the kids at school better understand. This way no one is surprised, and I don't have to explain that Ben is just my little brother. They will just know he is.

Q: What do you worry about most?

A: I worry about something happening to my family -- a death. I am really close to my mom. If something happened to mom, I guess I would take care of Ben and I wouldn't be able to talk to her and tell her my problems about life.

Q: What do you hope to do with your life?

A. I hope to do a lot of things. I want to stop global warming, make a peaceful world, save endangered species of animals and stop animal abuse, promote adoption of orphaned children, educate the world about overpopulation, and find a way to create appreciation amongst everyone for people of all colors, abilities, religions, and culture.

Q: Do you think that your life would be different if Ben wasn't your brother?
A: I wonder if I would be one of those kids that use the word "retard," and who doesn't care about the feelings of others? I hate that. I appreciate everyone. Everyday, the challenges and obstacles I face are not like those my friends face. Because Ben is in my life, I know how to handle problems, and don't get overwhelmed, like most teenagers do.

Also, I would never have met the great people I have met, like Gloria and June (Cal-State Northridge), the movie star Laura San Giacomo, Tony (Ben's inclusion teacher), Jan Ross (Ben's vision teacher) and Jim Ross (Ben's social worker) Kim (Alpha Resource Center), Nora (Paul's mom) and my new friend, Rebecca, from school. I would never have met all the good people that have become Ben's friends. He could have been put in an institution, and those friends would never have existed. That is hard to think about.

Q: What do you hope for Ben?

A: I want him to communicate. It is really hard for me to think about having all the same worries, concerns, thoughts, dreams and opinions that I have now, but being unable to communicate them to people. So, I know he thinks about a lot of the same things I do, and someday he will be able to tell people about what he thinks.

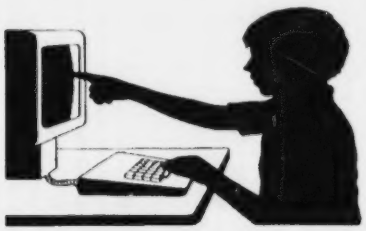
Continued on page 19

AN INTERVIEW WITH MICHELLE ON BEING BEN'S SISTER

Continued from page 18

I want Ben to have a home of his own when he grows up and to do the things he likes to do. I want him to continue to succeed in school and when he graduates from school, I hope he can do whatever he wants - get a job, to have friends and just be who he wants to be. He will want to be independent of mom and me. I know he will.

Q: Do you worry about Ben?



A: Yeah, I do. But, we take good care of him, and we make sure he stays healthy and is seen by all the right doctors. I don't worry too much. But this summer right before he went into the operating room to have his hip surgery I was really worried. I didn't want anything to happen to him and I was scared I would never see him again.

Q: What is your vision for the world?

A: I want to go out to the Blockbuster, to the grocery store, to the mall, and see that the world accepts everyone no matter who they are - that it be normal for Ben to be in those places and that I see all the other Ben's of the world there too.

Q: How do you expect to influence the change in society that will make your vision a reality?

A: I think by expressing acceptance of everyone, by being a positive role model for others and by being an advocate for the inclusion of people with disabilities. I think I should have a talk with our Governor (California) because he doesn't understand the vision for inclusion, or even give it a second thought. It is very sad, because it is about everyone, not just people with disabilities.

Q: What matters most to you?

A: My family, friends and pets.

Q. Where do people with disabilities belong in the world?

A. The answer is so simple. People with disabilities belong with everyone else, and I don't understand what is taking so long.

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Excerpts from Keynote Address by Corrina and Pearl Vessart

Continued from page 13

Smiles and darkness
Good and bad
School spun in circles
Nothing gained.

In the days of High School
Teacher left me.
Time to move on.
It was like generations we had together
Time to erupt and experience.

Oh Teacher!
Thank you for enlarging my world.
You taught me to read, write,
Type, in English and Braille.
Now, my eyes remain open
That longed for source of light,
Enabling me.
I am a new person.
Come and see,
I'm someone else...
Oh, Teacher....

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to the following Official Sponsors for their support of the 2001 TASH Annual Conference!

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R.J. Cooper & Associates

San Francisco Unified School District

Supported Life Institute

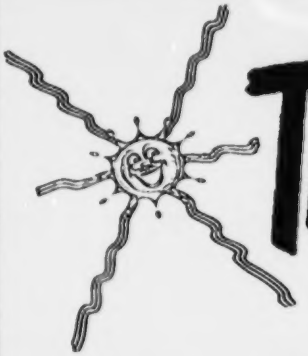
Los Angeles Chapter of the Autism Society of America

Westside Regional Center

Kathy Gee

Kathryn Peckham-Hardin

Richard Lee



Thanks

to the TASH 2001 Annual Conference Volunteers!

We couldn't have done it without you!

TASH Exhibit Hall

Thanks to the many exhibitors who helped make the Anaheim meeting such a success! There was a great mixture of products and services represented, and the dedicated exhibit time, poster sessions, and other special events kept traffic in the hall throughout the conference. We greatly appreciate the loyalty of those exhibitors that have been with us over the years, and hope that our newest exhibitors enjoyed the experience.

We look forward to seeing all of you in Boston in December 2002!

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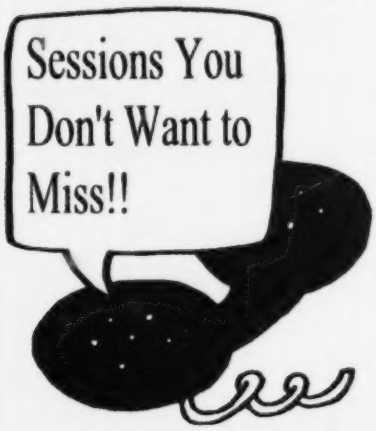


TASH is pleased to announce a series of teleconferences in April 2002! The teleconferences are being held in celebration of National Autism Awareness Month, a month that is dedicated to bringing autism into the spotlight to promote knowledge and public awareness. TASH is committed to the pursuit of equity, inclusion, and social justice for people who have been labeled with "severe" disabilities, including those whose label falls within the autism spectrum.

How it Works

The sessions take place on the phone. Each registrant or registered site (you can have as many participants at a site as you would like) receives handouts to view while listening to the presentation. Each session will last for 90 minutes. The first 45-60 minutes will include the presentation, with the remaining time for questions and answers with the presenters.

SCHEDULE OF SESSIONS (All sessions are from 1:00-2:30 PM Eastern Time; 10-11:30 AM Pacific Time) (please check www.tash.org for updates and complete session descriptions):

An Incidental Teaching Approach to Early Intervention for Toddlers with Autism (Tuesday, April 2nd)
Presenter(s): Gail McGee, Emory University School of Medicine

Pivotal Response Intervention (Wednesday, April 10th)
Presenter(s): Lynn Koegel, University of California, Santa Barbara

Supporting Students with Autism in General Education Classrooms: Designing Curriculum and Supports (Tuesday, April 9th)
Presenter(s): Rae Sonnenmeir University of New Hampshire, Institute on Disability; Michael McSheehan, Education & Technology Consultant

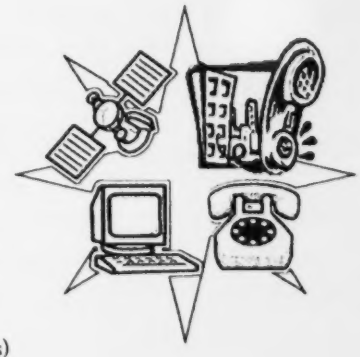
Supporting Students with Autism in General Education Classrooms: Designing Positive Behavior Supports (Tuesday, April 16th)
Presenter(s): Rae Sonnenmeir University of New Hampshire, Institute on Disability, Michael McSheehan, Education & Technology Consultant

Living Real Lives (Tuesday, April 30th)
Presenter(s): Jeff Strully, Dorothy Farrell, Laura Broderick, Jay Nolan Community Services

Understanding the Implications of Research (Wednesday, April 17th)
Presenter(s): Claire Maher Choutka, Parent, Graduate Student, Lehigh University

New Ways To View and Understand Autism (Tuesday, April 23rd)
Presenter(s): Anne Donnellan, University of Wisconsin, Madison and Martha Leary, Canada

Journey to Understanding: A Generational Perspective from Parents (Thursday, April 18th)
Presenter(s): Jamie Ruppmann, TASH, Catriona Johnson, Maryland DD Council and President of Howard County (Maryland) Chapter of Autism Society of America, and Barbara Cutler, Autism National Committee



Cost: TASH Members: $45.00 per person or $100 per site (sites can have unlimited listeners)
Non-Members: $55.00 per person or $125.00 per site
Family Members or Individuals with disabilities may take a $20.00 discount off the listed price

FOR MORE INFORMATION

Call 410-828-8274, send an e-mail to <autismseries@tash.org> or visit the TASH Website at www.tash.org

Lane Education Service District

Eugene, Oregon

Lane ESD invites applications for the following positions:

- **Teachers, Life Skills Education Program**
- **Speech and Language Therapist**

Lane ESD is located in Eugene, Oregon, a city of 137,000 situated at the southern end of the Willamette Valley about 100 miles south of Portland. Lane County's 4,500 square miles extends from the Pacific Coast to the Cascade Mountains. From Eugene, coastal beaches are one hour away to the west and snow skiing is one and one half-hours to the east.

Eugene and its surroundings provide an ideal living environment, rated one of the best in the United States. Outdoor and cultural activities abound. Eugene is home to the University of Oregon and Lane Community College. Education is a high priority for the citizens of Lane County.

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Book Clubs for Professional Development: Using Disability Literature

BY CAREN L. SAX

Everyone's hosting book clubs these days. Oprah Winfrey brought the activity to the attention of the country and helped to make it more accessible to everyone. It has become a social activity, a way to build community, a new way to reflect on personal experiences, and a vehicle to share intellectual and emotional reactions with friends and colleagues. Book clubs are being used in classrooms, both at the K-12 level and the post-secondary level.

Discussing literature in a book club format can help to evoke and explore emotions that are not easily discussed and to encounter the world in ways that we may never personally experience. Literature can give people "opportunities to share in the lives of others who ask the same questions they ask and who have the same types of experiences and concerns" (Carroll & Rosenblum, 2000, p. 620).

Consider the following comment from a student in reference to My Sister from the Black Lagoon (Fox, 1999), taken from an electronic discussion board created for a book club in a graduate course:

I read pg. 1-100, flash back time: I lived in North Hollywood about the same time as the author, and she could have been my next-door neighbor. In that time and family culture, you never put away family who had physical or mental disabilities. I have not, as of yet, seen any support from relatives for this family's hell. The author sure has a great recall of her day-to-day emotional and physical challenges at such a young age. With such a traumatic family life style, she has some deep-layered emotional scars. Yet, it did trigger some memories I'd forgotten or didn't want to remember. I guess this is the therapeutic value of the book?

One of the exciting aspects of using a book club to bring people together is that there are no hard and fast rules. In fact, the group must create its own set of rules by which to conduct their interactions.

This student's book club focused on literature that included characters who had disabilities. The book club was designed as part of an introductory course on rehabilitation foundations and demonstrates one use of book clubs in the academic setting. However, the format and process of book clubs can be easily modified for use in staff development, professional growth, and organizational change processes.

This article describes the process and potential contexts for using book clubs as a vehicle for introducing and reflecting on disability issues. Book clubs can be used as a powerful instructional strategy for preservice education, inservice training, and addressing organizational issues, as well as a way to promote lifelong learning. A list of recommended books is included.

Book Clubs and Disability

Books by and about people with disabilities have existed for a long time. In the past decade, an increasing number of books demonstrate new attitudes about disability, culture, and society (Davis, 1997; Longmore & Umansky, 2001; Shaw, 1994). These books reflect perspectives about disability that challenge stereotypes and demonstrate new perspectives through such powerful titles as: No Pity: People with Disabilities Forging a New Civil Rights Movement (Shapiro,1992); Nothing About Us Without Us (Charlton,1998); Claiming Disability: Knowledge And Identity (Linton,1998); and Beyond Ramps: Disability At The End Of The Social Contract (Russell, 1998).

More and more people with disabilities are telling their stories through biographies and autobiographies. Through this genre, individuals with disabilities provide insight into their personal experiences, describe their perceptions of the world, and share reactions that they observe in others.

Other stories are being told through novels and short stories that present people with disabilities in a variety of roles: brothers, sisters, sons, daughters, parents, friends, and lovers. These books compel the general public to view disability as part of the range of human experience.

Children's and young adult novels have been published more recently that include characters with and without disabilities relating to one another in a variety of community settings. These stories go beyond including a character merely because of a disability; rather, the disability is only one of many characteristics that makes up an individual. This new selection of children's picture books and books written for young readers can be used with adults to explore images and attitudes that are different from books that were available decades ago.

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Book Club Strategies

One of the exciting aspects of using a book club to bring people together is that there are no hard and fast rules. In fact, the group must create its own set of rules by which to conduct their interactions. The general purpose of the activity should be to examine values, beliefs, behaviors, and attitudes about people with disabilities and other disability issues.

The following steps are provided as a starting point. While this structure is based on a book club that will be held for at least five sessions, the number of meetings and duration of time between meetings should be determined by the group. The books in this example are read one third at a time with a discussion held after the members have read the designated pages. The process may be modified along the way if the group decides to do so.

Identifying book(s) for the club. This decision may be made by the group collectively, depending on the purposes in mind. If the book club is being used in a preservice or inservice setting, the instructor/facilitator might choose books that address specific topics. If more than one book is used, the distribution may be random (i.e., picking titles out of a hat), or purposeful (i.e., assigning people specific titles). Groups might all choose the same book or small groups within a larger group might be formed according to the book titles that are selected.

Deciding on modes of reflection and communication. While face-to-face group meetings are typically the medium for communication, electronic discussion boards may be used to enhance the dialogue between scheduled meetings. Journals, tape recorders, even video recorders are often used by individuals to record their impressions before and after book club meetings. Depending on the learning styles, comfort levels, and technology access, the group may use one or more of these options.

Brainstorming "rules of engagement." The group must decide how to approach at least the following parameters: how many pages to read for each meeting (and that everyone agrees to read those pages); how many meetings to hold; length of each meeting; speaking and listening guidelines; roles and responsibilities of each member (e.g., facilitator, timekeeper, notetaker, mediator/clarifier, etc.).

It is essential that the members of the group understand their responsibility for their own growth and that they support others to do the same. The group should set the guidelines before the reading begins so that everyone goes into the book club with similar expectations. These guidelines should be revisited at the beginning of each session to determine if modifications are necessary.

Session I: Predictions to start conversations. Questions may be presented to help generate conversation: What can you tell by the book cover? The title? The book notes? Has anyone read any reviews? Members could also be asked to search out reviews. Questions are often developed by the instructor/facilitator; however, the group members may add their questions and comments to address related issues. For groups using a variety of books, one set of general questions may be generated for all the books and a second set of questions designed to address each book.

Session II: Identify goals for the discussion. During this session, members of the group share their first reactions. They identify stereotypes that are present early on and make predictions about the next part of the book. Discussions typically include reactions to the setting, beginning character development, language, and other elements of style that make the book engaging right away or force the reader to wait until it gets better. Are people with disabilities presented in stereotypes? Are the settings contrived? Are the relationships between people with and without disabilities represented realistically and reciprocally? How do these images compare with other books that the members have read, or that are traditionally represented in literature (e.g., Wolfensberger, 2000)?

Session III: Expand on the initial issues. By this session, readers are developing a better feel for the characters, plot, and direction of the action. Do the readers identify with the characters? Is the story realistic (and by whose standards)? Does it relate to anyone's personal experiences? When members share references to specific incidents, it is helpful to point out page numbers and paragraphs to help clarify and support impressions. New predictions can be made about the ending of the book and initial predictions may be reassessed to determine the accuracy.

> ***Using literature that features characters with disabilities helps us all to consider different perspectives; outcomes from using book clubs are limitless.***

Session IV: Discussing the ending of the book. During the last session, members often admit that they read ahead to the ending before the assigned pages were due. Is so, did it make a difference in the way that they perceived the book as compared to others who read the sections as designated?

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Were the predictions correct? Was the character development consistent? Were stereotypes used regarding people with disabilities? If not, how were they portrayed? Evaluate the ending as to its likelihood, predictability, interest. Did the incidents and characters in the book reflect any personal experiences? How did they compare? Identify new information about disabilities and/or information that changed your perceptions? Would they recommend the books to others?

Session V: Reflecting on and demonstrating what was learned. Keeping a journal throughout the book club adds another level to the reflection component of the sessions. Some people find it easier to write their reactions first before sharing them with the group. Journaling can also be an effective way to record changes in perceptions and can document the effects of a group process on individual perspectives. Depending on the context, the members can create a final project to demonstrate the impact of the book and the book club discussions. When used in a class setting, the final report should be something other than a written book report. Giving students an opportunity to demonstrate what they have learned in forms other than a traditional report provides insight into attitudes that even the students themselves may not have recognized.

For example, students may create a role-play or act out excerpts from the book, use photography to reveal their insights, or design activities to teach others about disability issues presented in the book. Book club members have reported that they were motivated to learn more about specific disabilities and often have integrated that information into their final reflections.

Contexts for Book Clubs

As mentioned earlier, book clubs can be used with students from kindergarten through postsecondary levels. In addition, book clubs may be incorporated into staff development for schools, community organizations, parent groups, and other non-profit associations. Teachers interested in integrating disability literature in the range of books addressing diversity issues can use a book club format with one another to prepare for using it with students.

Paraprofessionals in classrooms as well as in transition programs can benefit from using book clubs as part of their inservice training. Staff, whether in schools or community organizations, are often unofficial public relations representatives when they interface with the community for job development, job training, or other community instruction. Reflecting on their own attitudes about people with disabilities can help them model behaviors of acceptance. Parent groups can use book clubs for training with other parents, and can also use them to create vehicles for collaborating with schools.

While face-to-face discussions with book clubs may be preferred by many, holding online discussions is another option. Designing web-based discussion boards where book club members can post their reactions to their books provides a forum that can be used to enhance face-to-face meetings or in lieu of them. Comparing reactions with people from other geographical locations can add another dimension to the discussion. In addition, a written record is then available that can be shared with other groups. When the discussion board is used between meetings, members can post their responses as soon as they come to mind. Hearing others' reactions often influences the perspectives of the group members as they read the rest of the book.

Lessons to be Learned

Using literature that features characters with disabilities helps us all to consider different perspectives. Outcomes from using book clubs are limitless. Members may write their own books or illustrate existing books to use for another selection. Using such books opens the discussions to learning more about specific disabilities, accommodations and modifications that people with disabilities use, as well as legislation that has been passed to ensure the rights of people with disabilities.

Further exploration might be done in the area of how images of disabilities have changed throughout history by researching images in film, artwork, popular press, and advertisement. Surfing the Internet for stories about people with disabilities reveals so much more about what people with disabilities can do, rather than what they cannot do. This is the lesson still to be learned by many.

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Bauby, J.D., & Leggatt, J. (1997). *The diving bell and the butterfly: A memoir of life in death.* New York: Alfred A. Knopf.

Bender, K. (2000). *Like normal people.* Boston, MA: Houghton Miflin.

Dart, I. R. (1999). *When I fall in love.* Avon.

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Handler, L. (1998) *Twitch and shout: A Touretter's tale.* New York: Dutton.

Hockenberry, J. (1995). *Moving violations: War zones, wheelchairs, and declarations of independence.* New York: Hyperion.

Kleege, G. (1999). *Sight unseen.* New Haven, CT: Yale University Press.

Kuusisto, S. (1998). *Planet of the blind.* New York: Delta.

Mairs, N. (1998). *Waist-high in the world: A life among the nondisabled.* Boston, MA: Beacon Press.

Ototake, H., & Harcourt, G. (2000). *No one's perfect.* Tokyo, Japan: Kodansha International.

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Sidransky, R. (1990). *In silence: Growing up hearing in a deaf world.* New York: St. Martin's Press.

Stallings, G., & Cook, S. (1997). *Another season: A coach's story of raising an exceptional son.* New York: Broadway.

Stewart, J. (1989). *The body's memory: A novel.* New York: St. Martin's Press.

Vigand, P., & Vigand, S. (2000). *Only the eyes say yes: A love story.* New York: Arcade.

DISABILITY LITERATURE (Young Readers)

Fleischman, P. (1999). *Mind's eye.* New York: Henry Holt.

Holt, K. W. (1998). *My Louisiana sky.* New York: Dell Yearling.

Mikaelsen, B., (1998). *Petey.* New York: Hyperion.

Newth, M. (1995). *The dark light.* New York: Farrar, Straus, and Giroux.

Tashjian, J. (1997). *Tru confessions.* New York: Henry Holt.

Trueman, T. (2000). *Stuck in neutral.* New York: HarperCollins.

DISABILITY LITERATURE (Children's Picture Books)

Dedieu, T. (1996). *The boy who ate words.* New York: Harry Abrams.

Gilmore, R. (1999). *A screaming kind of day.* Toronto: Fitshenry & Whiteside.

Lakin, P. (1994). *Dad and me in the morning.* Morton Grove, IL: Albert Whitman & Company.

Morrison, T. (1999). *The big box.* New York: Hyperion.

Shannon, D. (1998). *A bad case of stripes.* New York: Scholastic.

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Priscilla Newton, *Editor*

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Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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TASH CONNECTIONS

Equity, Quality and Social Justice for People with Disabilities

Inside This Issue

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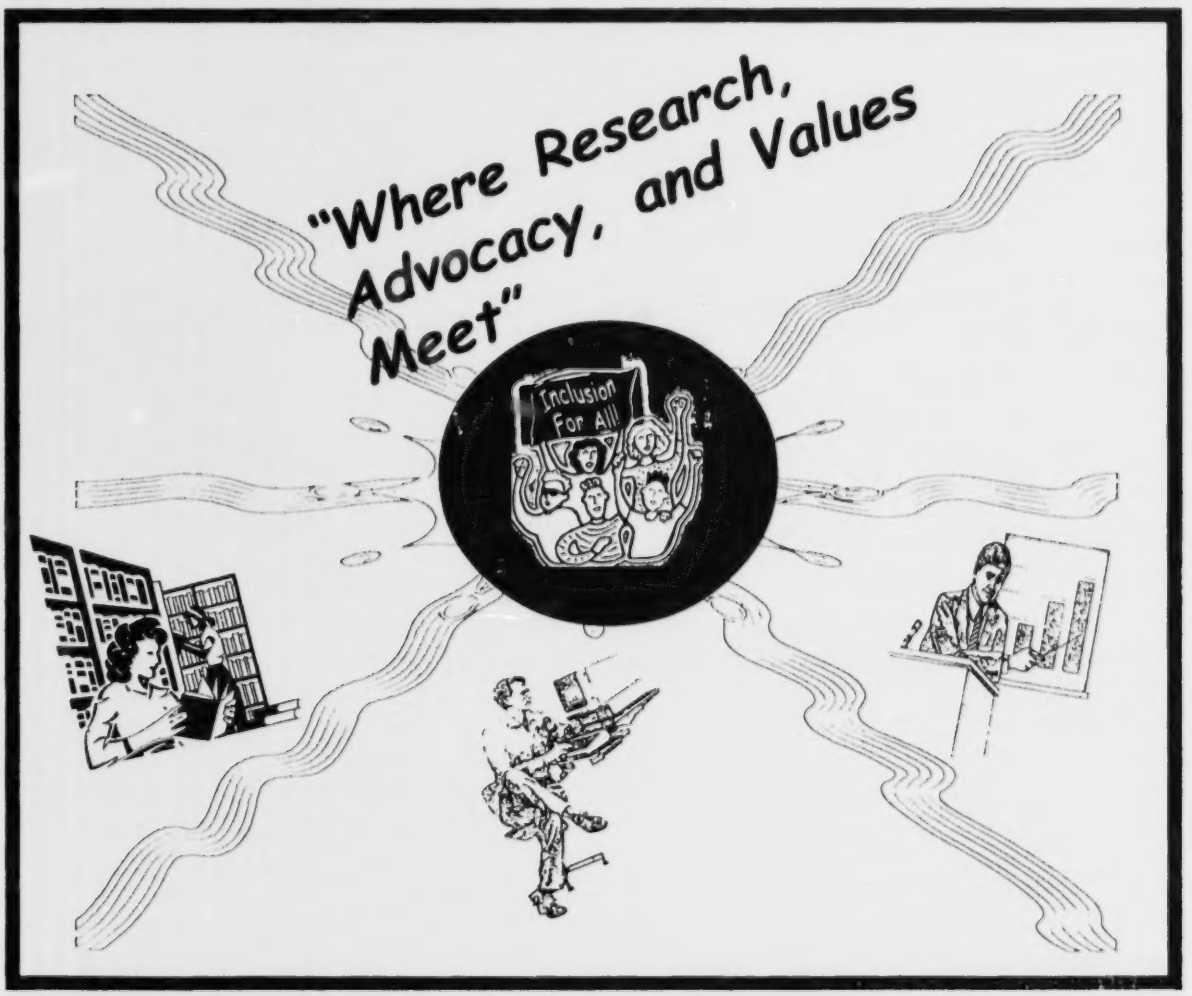
- Research in Support of Advocacy
- Action Research at the Center on Human Policy
- Personal Musings on Research and Data-Based Advocacy



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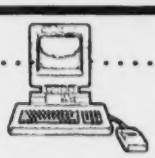
TASH's focus is on those people with disabilities who:

- Are most at risk for being excluded from the mainstream of society
- Are perceived by traditional service systems as being most challenging;
- Are most likely to have their rights abridged;
- Are most likely to be at risk for living, working, playing, and/or learning in segregated environments;
- Are least likely to have the tools and opportunities necessary to advocate on their own behalf;
- Historically have been labeled as having severe disabilities; and,
- Are most likely to need on-going, individualized supports in order to participate in inclusive communities and enjoy a quality of life similar to that available to all citizens.

TASH accomplishes this through:

- Creating opportunities for collaboration among families, self-advocates, professionals, policymakers and other advocates;
- Advocating for equity, opportunities, social justice, and rights;
- Disseminating knowledge and information;
- Supporting excellence in research that translates to excellence in practice;
- Promoting individualized, quality supports;
- Working toward the elimination of institutions, other congregate living settings, segregated schools/classrooms, sheltered work environments, and other segregated services and toward replacing these with quality, individualized, inclusive supports;
- Supporting legislation, litigation and public policy consistent with **TASH**'s mission; and,
- Promoting communities in which no one is segregated and everyone belongs.



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From the Executive Director

BY NANCY WEISS

The idea for an issue of TASH *Connections* devoted to the relationships between research and advocacy sprung out of an exciting session that was held at the 2000 TASH Conference in Miami. Craig Kennedy, Linda Bambara, Phil Ferguson, Fredda Brown, George Singer and Daniel Dickman led a discussion that looked at ways that research and advocacy can work together to promote social change. Later, the JASH Editorial Board met and the discussion that began at the session entitled, *"Where Science, Values and Advocacy Meet,"* continued.

I expressed concern to the group about phone calls I occasionally get from parents, self-advocates and other advocates who say (basically) "why don't you save some money for TASH and stop producing the peer-reviewed journal (formerly called JASH; now called Research and Practice for Persons with Severe Disabilities)?" Parents and other advocates would complain that the Journal contains all this "research" (said as if it was a dirty word), that they can't imagine anyone actually reading the thing, and that even if people did read it, the stuff that's in there doesn't mean anything in the real world, anyway.

Then, I'd get other calls. The same advocates who had advised us to save money by not publishing the Journal (or at least same types of folks!) would call when they were getting ready to go to an IEP meeting, a city council meeting, or to court to fight for something they or their family member needed, wanted and deserved. These callers would say, "Can you send some research that proves that inclusion (or positive behavioral approaches, or assistive technology, or supported employment, or whatever it was that they were fighting for) works?" When they needed to fight for what they or their family member needed, they realized that one can't ask for progressive services and supports just because they are a good thing; advocates have to be able to prove that these approaches work. They realized that the kind of progressive research found in our Journal is important. It is true that we want people to lead real lives, have real jobs, be included in regular educational settings and have access to positive behavioral approaches because these things are good and right ... but we also know that research demonstrates that people make more progress in the community, are happier and more productive in real jobs, learn more in inclusive settings, and so on.

The idea for this issue of TASH *Connections* was born. George Singer and Joseph Scotti graciously agreed to co-edit the issue with me. We wanted to feature articles that would help build an understanding of the positive influence advocacy goals have on research agendas and also how important progressive research can become for advocates as they fight the good fight. The articles contained in this issue describe ways that advocates depend on and use research to achieve social change agendas and ways that advocacy efforts can have an impact on what researchers choose to study.

I often tell people that TASH is unique among disability organizations in that we are not a professional association, not a parent association and not a self-advocacy organization — rather, we are a true hybrid of all three. We are, in the truest sense of the word, an advocacy organization that brings people from all walks of life together around a common belief system. TASH is not about research OR advocacy. TASH is about research AND advocacy. Neither can have impact without the other. It is our hope that this issue of TASH *Connections* will help readers to realize that both research and advocacy are essential to accomplishing TASH's mission.

TASH would like to acknowledge the time, energy, and support of the special co-editors for this issue, Joseph Scotti, George Singer, and Nancy Weiss. From the initial call for papers to the final editing of the submissions, these individuals provided wisdom, guidance, and encouragement throughout the involved process of bringing this issue of TASH Connections to finality.

Our sincerest thanks for your hard work and commitment to this issue!

Priscilla Newton, Editor, TASH Connections

ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of JASH for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this:

Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year — in addition to an extra full year's worth of journals!

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To learn more about TASH's Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

What Difference Does It Make, The Color of Your Parachute?

BY FREDDA BROWN

I guess I'm confused! I have attended meetings at TASH and elsewhere and the participants asked to: "Raise your hand if you're a researcher;" "Raise your hand if you're an advocate;" "Raise your hand if you're a parent;" "Raise your hand if you're a teacher;" and so on.

I must confide that I get confused. I'm not sure when to raise my hand! I want to say, "What do you mean by researcher? What do you mean by advocate? Can I raise my hand two times? Can I raise my hand three times? Or must I raise my hand only once?" The pressure is on. I try to inconspicuously peek to see how others respond — people who I know do similar types of things as I do; but then I feel like I'm in 6th grade and the teacher might accuse me of looking at my neighbor's answers!

My father (a salesman of milk, light bulbs, and other necessary items for daily life) used to begin many life lessons to me with the phrase, "In my line of work...." So, to borrow his words ... in my line of work, I can't distinguish between the need for, the conduct of, and the use of research versus advocacy. I guess it is not a distinction that holds any relevance to me in "my line of work." "My line of work" involves many different things, and different things at different times. Let me take one of these things as an example — my sometimes role as an Educational and Behavioral Consultant.

In my sometimes role as an educational-behavioral consultant, I look for the best strategy to reach the targeted goal or objective (as determined by the person I am supporting, his or her family, a school, and so on). For example, how do I support a school to maintain a child's placement in an inclusive classroom when he is engaging in very disruptive behaviors? How can I get a residential program to stop using coercive strategies to decrease problem behaviors and increase adaptive behaviors? In these contexts, I don't think of myself as a "researcher," and I don't think of myself as an "advocate." I think of myself as just one person trying to work to improve the lives of individuals with disabilities and their families.

Each situation must be approached with the goal of achieving our agreed on purpose — and how that is done must be individually determined. We must look at the situation and try to best determine, from the unique context, what the best action, or typical combination of actions, would be.

To demonstrate this, I will briefly discuss one of my experiences a few years ago as an expert witness in the cases of two young women who were receiving contingent electric shock on various body parts via the GED (Graduated Electronic Device), as well as other aversive strategies. In each case, my job was to meet the young woman, examine her educational and behavioral programs, and meet with the designers of the program. Then I was to go to court to testify about the appropriateness of the programs. Considering our (as a field) historic failure in preventing the use of contingent electric shock in this specific facility, it was an ominous, overwhelming, and somewhat frightening task! I inquired about the strategies used by past experts and went back and forth about how I would attempt to convince the special master appointed by the court that there were indeed many other (proven, effective, positive, constructive, humane) roads to take with these two women (not to mention everyone else in the facility).

I took a different approach in each of the two testimonies. In hindsight, perhaps these approaches could be loosely categorized into the "research" approach and the "social justice" approach. In the first of the two cases, I was the traditional "expert" witness, that is I presented a coherent, scholarly analysis of the empirical research in the field, painstakingly critiqued the ongoing aversive programs, and offered recommendations based on the current research and best practice standards in the field.

I wanted to leave in the court's mind no doubt that we now have a proven technology (as empirically demonstrated by research) to not only decrease the "dangerous" behaviors, but to truly and positively impact the quality of life for this individual. I prepared a 22-page report, including 4 pages of current references. It was quite the volume!

Following this, my oral testimony in court went well; the attorneys asked of me pertinent and revealing questions, to which I responded with scholarly confidence. In our (of course biased) opinion we in no uncertain terms demonstrated that this young woman's educational and behavioral program was, beyond the shadow of a doubt, inappropriate and that we absolutely have the skills and (research-based) strategies to address her needs in positive and effective ways.

We all have learned the negative impact of labeling people with disabilities. We must also acknowledge that it is unproductive to label or categorize any person's efforts to work toward our common goal, and I believe that we at TASH do have a common goal. Perhaps trying to categorize who we are or what we do diminishes and demeans our efforts.

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What Difference Does It Make, The Color of Your Parachute?

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The outcome? The major points of my written and oral testimony were to join the testimony of the long list of other experts, that is, what I had to report was virtually ignored in the court's findings. In fact, the few statements of my testimony that were included were statements that were taken out of context and were made in response to cross-examination:

"Dr. Brown, ...did acknowledge, however, the problematic behaviors in this case appear to have decreased."

"...She further stated that she would not recommend discontinuance of the GED unless a totally restructured program was introduced."

An abysmal failure. So, time for the next report and testimony. How many times can I (and all the past experts) report the research that we have to support our positive strategies? How many times can we critique and determine the inappropriateness (even according to the most traditional behavior analysts) of behavioral procedures used? And yet, according to all the past court decisions there are sufficient data to support the continued use of the aversive procedures.

I decided if I couldn't convince the court with my research-based arguments, I would try some jargon-free "human appeal." I would make a plea to the judge, tell him to try to imagine the degradation of this young woman naked in the bath, while restrained by her wrists to the wall, and being bathed by staff. I would tell the judge how truly painful the shock is (which I requested that the opposing attorneys and the judge try, as I did). I would tell the judge that just because there are no physical marks that remain from each of the hundreds of shocks a person might get in a day, that there are emotional scars just like there are with woman and children who are abused. And let me tell the judge that this woman can, indeed, have input into her program, regardless if the opposing attorney states that she is incapable of such contributions and self-determination. We have proof of this — each and every time that she attempts to remove the shock device (which, of course, is followed by delivery of another shock!). And so on, and so on. Following are some of the court's findings, and perhaps as you read, infer what the court might have been thinking about the weight that an advocacy organization might (or might not) carry:

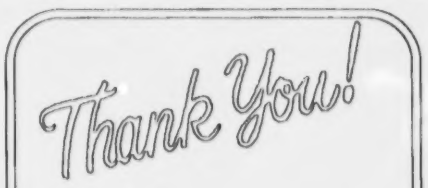
"Ms. Brown conceded that she holds a leadership position in the organization known as TASH, whose goal includes a call for the ban on all aversive interventions, and that she has lobbied for a federal law to ban all aversive interventions in schools. ...Although Ms. Brown appeared knowledgeable in the subject matter herein, and she did appear to be genuinely concerned, I cannot give weight or consider her testimony because of her prejudice against use of the GED or any other aversive treatment."

Neither testimony was effective. We were not successful in changing attitudes or practices for people with severe disabilities in general, and certainly made no difference in the lives of these two young women. One testimony relied on research, the other on a humanistic and social justice argument. And I think it would be difficult to argue that advocacy was not the foundation of both situations. The question now remains, how do we come together to address such challenges — to come up with an innovative approach (regardless of what we might call the approach) to effectively fight such injustices? At this point, our voice has been heard, but it doesn't matter.

We all have learned the negative impact of labeling people with disabilities. We must also acknowledge that it is also unproductive to label or categorize any person's efforts to work toward our common goal, and I believe that we at TASH do have a common goal. Perhaps trying to categorize who we are or what we do diminishes and demeans our efforts. TASH has been a home to so many of us for so many years. Any division of efforts reduces our collective strength.

Portions of this article were presented at the Annual TASH Conference, Miami, Florida, 2001.

Dr. Fredda Brown is a member of the TASH Executive Board and editor of Research and Practice for Persons with Severe Disabilities (formerly JASH).



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David Ferleger

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Cheryl Whiting-Wright

Don't forget about TASH's lifetime membership option! Lifetime membership entitles you to full international and chapter member benefits for your lifetime, and the cost can be remitted over several monthly payments.

If you are interested in becoming a lifetime member of TASH, please contact Rose Holsey at 410-828-8274, ext. 100.

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TASH: Public Policy In Action

The House Education and Workforce Committee has approved a bill to overhaul the Office of Educational Research and Improvement (OERI). This office currently conducts research and demonstration projects to help improve education, collects data on the status and progress of schools and education nationwide, and provides technical assistance and information to those working to improve education. Titled the "Education Sciences Reform Act," the bill proposes to replace the Office of Educational Research and Improvement with a new Academy of Education Science, intended to be the infrastructure for educational research and statistical program evaluation within the Department of Education.

In addition, the bill requires that all federally funded activities meet standards intended to assure "scientifically based research" and seeks to make technical assistance more "customer-driven" and "accountable to school districts, states and regions."

The House Education and the Workforce Committee approved the Keeping Children and Families Safe Act on March 20, 2002. The bill reauthorizes the Child Abuse Prevention and Treatment Act (CAPTA). This bill primarily focuses on preventing child abuse and family violence and protecting and treating abused and neglected children. It also provides for extending the authorization of the transitional housing assistance program, which awards grants that provide housing assistance to victims and their dependents fleeing a domestic violence situation and has several new provisions aimed at improving the training, recruitment and retention of protective services personnel.

Representative Bobby Scott (D-VA) championed a new provision that will require state child welfare agencies to establish policies and procedures to refer young children who are part of the child welfare system to the early intervention services supported by Part C of the Individuals with Disabilities Education Act. While such referrals are made in some states, it is not standard practice. As a result, many young children who have acquired a disability or developmental delay as a result of child abuse do not receive necessary early intervention services. The Scott amendments were approved at the full committee mark up of the House bill.

The Senate is currently drafting their own Child Abuse Prevention and Treatment Act legislation. TASH will be working with other child advocates to secure language in the Senate bill that will correspond to the Scott provisions in the House version. Representative Scott was recently honored by TASH for his longtime legislative activities on behalf of people with disabilities and their families.

The Education Sciences Reform Act, H.R. 3801, and the Keeping Children and Families Safe Act, H.R. 3839, are available online at www.edworkforce.house.gov

TASH Government Relations Director Jamie Ruppmann was an invited presenter at the Brain Injury Association's "Public Policy Conference 2002." Jamie gave a presentation entitled *"Critical Issues and the IDEA: Myths and Rhetoric versus Reality."* The presentation will soon be available on the TASH website.

In response to the strong interest in IDEA "reauthorization" expressed by TASH members, we are converting the Government Affairs listserv to focus on issues related to education reform and special education support and services. The new listserv will be titled TASH IDEA WATCH.

For more information about TASH IDEA WATCH or other questions or concerns about legislation or public policy, contact Jamie Ruppmann, jruppmann@tash.org or call (410) 828-8274 x. 104.

It is with great sadness that we pass on to members of the TASH community the news of the sudden death of Bob and Martha Perske's daughter, Dawn Clayton. As many of you know, Bob and Martha have been friends and supporters of the work of TASH for many years.

We have received several requests from members asking where donations can be made in Dawn's name. Bob and Martha have been very touched by such kind expressions, and ask that they be sent to:

The Richard Lapointe Defense Fund
c/o The Arc of Connecticut
1030 New Britain Avenue
West Hartford, CT 06110

From Research to Practice

See that handsome man carrying furniture? That's Stefan Ruppmann getting more of the life that he and his family talked about and dreamed of for so long.

On Saturday, March 8, Stefan moved into a condominium owned by his friend, Brian, another self-advocate and now "house mate."

The day was full of joy and promise, but also nostalgia for the hustle and bustle of a house where children once lived -- now quiet.

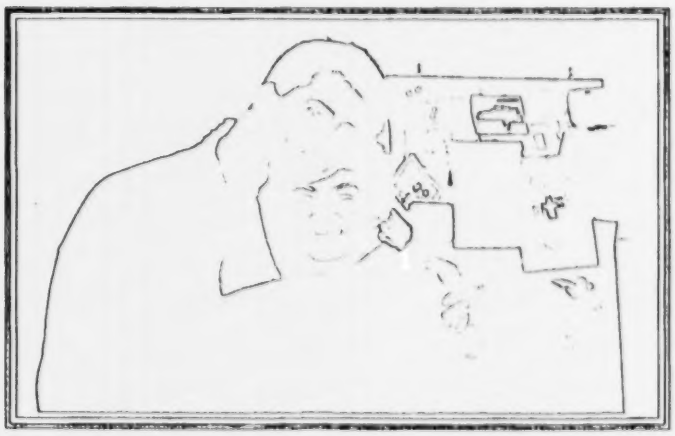
The weeks since "Stefan's move" have been full of memories of the path our family traveled to reach this day and of the companions who shared our journey.

Many of those fellow travelers were other families, but a large number were researchers and truth seekers from the professional community. People whose passion and vision warmed my heart and reinforced my determination that Stefan should, could and would have a full and happy future. I remember the first time I heard Anne Donnellan and Gary LaVigna speak about the positive and respectful ways people with disabilities could be successfully supported -- and took seriously Anne's urging to make the "least dangerous assumption" about my own son, as well as the children I would support as an advocate.

I still remember crowding into an overflowing workshop where Barry Prizant talked about his research and ideas about the positive links between echolaic speech and children with autism. His words encouraged us to incorporate that much more positive outlook into our family's ideas about Stefan as a communicator.

Those workshops, newsletter articles and personal contacts helped us to see Stefan's growth and development as leading to something and somewhere that could be happy and productive — very different messages than those we got from the textbooks and medical information we had been given when it became clear that Stefan was probably a person with autism.

The research bolstered our skepticism about segregated learning environments, about grouping children together by label, about isolating Stefan from his community so he could have "special" activities tailored to his "special" needs. I still have a tattered copy of Steve Taylor's *Caught in the Continuum* in my home files. We relied on that cutting edge research when we weren't sure which path to choose. We would think about that "good life" Stefan wanted and choose the way most likely to get him there.



Today Stefan has work that is important, he has friends who love him dearly and who choose to be with him, and now he has a terrific new home to share and to care for. The very best "research to practice" outcomes we could have imagined.

—JAMIE RUPPMANN

Why Bother to Prove What I Already Know?

BY IAN M. EVANS

One of the most enjoyable experiences of my professional life in the United States was to go down to Washington, D.C. to read grant proposals for what was then the Office of Special Education and Rehabilitation Services (U.S. Department of Education). This was truly an event to savor.

After walking along miles of stark corridors in some dreadful Federal building, one eventually came to cramped offices piled high with final research reports, where one would meet the other readers and be briefed by a senior OSERS official as to the gravity of the task ahead. You would then walk back down to the Capitol Holiday Inn (no expense spared for us readers) where a van had delivered a huge pile of proposals. For the next three days and nights one never left the hotel room except for two visits back to the principal's office for a stern check on whether you were making due progress with your reading and your rankings.

For absolutely no pay some of the best minds in special education in the country would be working like the proverbial beavers to award grants to a handful of researchers. A casual perusal of the awards, especially if you were a politician of the Golden Fleece persuasion, might lead you to think that funding was generous, with thousands, sometimes millions of tax dollars going to both novice and leading researchers. But the total annual budget was a drop from the Federal bucket, the competition fierce with many excellent projects unfunded, and the more creative but thus risky proposals declined. Why then, was the task of reviewing these applications so rewarding? Because as a peer reviewer, with no conflict of interest or personal axe to grind, I felt I could promote the search for knowledge in special education by encouraging hard-working scholars to invest their energies and skill in novel approaches for people with severe disabilities.

Not all significant research is publicly funded and much creative work is carried out with the limited support available in universities and the even more modest resources in schools, clinics, and other centers of expertise, especially where practitioners have been trained in action research models to think scientifically. But in every case it has to be planned, approved by human subjects ethics committees, implemented, evaluated, the findings distilled in some acceptable way, written up, submitted for publication, reviewed, and revised. Eventually a research paper might appear, heavily shaped by the demands of editors and expected standards of data interpretation currently esteemed in the field. So next time you read a research paper in a peer-reviewed journal, skim it through and think "I could have done that," spare a second thought for the authors who might have been working on the project for five years or more. An even more probable thought is "I knew that already."

> The essential criterion of methodologically sound research – and its primary function in social science – is that it is more objective than simply our opinions or our desire for something to be true.

With the exception of biomedical research, much of the formal study in disabilities is concerned with education, behavior change, social influences, and improved description of syndromes. As a result, our research is less about discoveries of natural phenomena and more about the obvious — once it has been pointed out. Often the goal is to explore the outcomes that are possible when optimal environmental conditions are created: social engineering rather than technological innovations like CDs, targeted drugs, or cloning. Rather than proving that something should be done a certain way, social science inquiry demonstrates that something can be done. For example, we have good studies showing that children labeled with very significant disabilities can be included successfully in regular schools, but such research does not prove that inclusion works regardless. Similarly, we have some studies demonstrating that the outcomes are not always as promising as expected, and these studies do not prove that segregation is permissible.

Partly because of its origins in behavioral science, the education and habilitation of people with the greatest support needs has for the past 40 years been grounded in sound empirical demonstration rather than popular fad. This professional work ethic has had the tremendous benefit of convincing all of us that we wanted evidence our children or our clients were indeed making meaningful gains. Striving for measurable outcomes can get a bit perverted, and IEPs sometimes have ludicrous quantitative criteria stuck in to gloss them up, but it is now a widely accepted standard of practice that progress will be documented in measurable ways. For a given individual we don't accept that someone's impression of change is good enough, however confidently

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asserted. Visionaries like Lou Brown said "pre means never," curriculum experts anticipated the needs of "future environments," and research scientists busied themselves with "celeration lines" — but the goals were all the same: in severe disabilities services we demand evidence of meaningful change.

But because of this long love affair with scientific evidence, many scholars in our field have only slowly come to understand that the reforms advocated for people with disabilities are not recommended practices because there are data to verify them, but because they have come to be seen to be right. Does this mean that what are considered "best practices" in special education have no empirical support? No, what happens is that over time there is an accumulation of confirmatory evidence, some simply experiential and reported informally, but most based on verifiable results that can be replicated from some kind of education trial, that a practice has merit. Initial empirical findings are further modified by extensive practical experience.

For example, in the early days of applied behavior analysis it was soon demonstrated that precision teaching, based on repetitive trials in small steps with high levels of feedback and reward, could successfully impart skills to people who had not previously been thought capable of learning such tasks. But additional experience modified this conclusion in important ways: it is preferable for the skills being taught to be functional; that the learning trial should be built into natural opportunities to use or rehearse the skill; that natural social reinforcers and the pleasure of accomplishment are generally better than artificial rewards such as candies or tokens.

Some of my own work with Fredda Brown confirmed that when skills were taught as functional routines, people labeled with severe disabilities could acquire substitutable, alternative ways of meeting their needs, and it was these outcomes that we needed to measure, not some predetermined behavioral baseline. As these new insights revised earlier methods, recognition of their practical advantages outstripped the formal operant research literature, which was still locked into tedious demonstrations that repetitive trial instruction resulted in good acquisition of discrete behaviors. Many researchers who were documenting these latter truths were overly influenced by the methodologies from the animal lab and thus did not factor into their evaluations of success such additional variables as quality of life, meaningfulness of the outcome, or developmental appropriateness (social or "educational validity"). Thus, there developed some degree of conflict between researchers advocating rigorous evaluation methods and those innovative practitioners who took the broad ideas generated by the early research — the principles — and adapted them for their own needs, for the needs of different cultural groups, and for the practical realities of ordinary classrooms or clinical settings.

Research has multiple functions, only one of which is to try to prove the superiority of a particular approach. In fact that function is one of the most limited because it is often difficult to generalize specific findings from the rarified conditions of the research lab to the everyday complexity of the typical classroom or family. Interventions that seem successful in tightly controlled experimental conditions are not usually nearly as efficacious in more typical settings. And it is really hard to make a fair comparison between an innovation and the same old "treatment as usual." Where, for example, could one find a really first-class segregated special education program that has essentially the same characteristics as another really excellent inclusive program? When things are very different there is no point comparing them; it is a bit like asking if the citizens of a given city would benefit most from a new art museum or a new baseball stadium. That is not a scientific question, although social science can inform decision making by, for example, ensuring that information relevant to the decision is properly gathered. So if all this is true, what other functions does research serve that seem particularly useful?

> We perhaps need to consider a little better who uses research findings — who are the real consumers? Of course other professionals are the primary audience, and that is how it should be if one goal is to inspire innovation in practice. But research should be presented in a way that other interested persons — all stakeholders — can appreciate its significance.

One is that research in our field helps articulate what is possible. Mark Gold's famous study of young people assembling the bicycle brake didn't prove that people with intellectual disability are good at fixing bikes. It demonstrated that negative expectations could be confounded with careful instruction — that we always needed to "try another way."

Another function, somewhat similar, is that research illuminates a facet of a phenomenon that has not previously been considered. By observing what actually happens in an inclusive classroom program, Christine Salisbury and I were able to notice that while physical inclusion was occurring, some teachers still failed to find ways of making it possible for a child functioning at a very different level to participate in a given activity. We also noted that the other children in the classroom were often better able to identify these lapses and prompt more equitable teacher behavior. We did not expect that the world would then train typical children to be the inclusive education police (after all, they had their own, slightly different ways of excluding some peers), but it did result in the possibility that a valuable element of an inclusive educational program is to insure that the other children understand one of the principles of inclusion,

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namely fairness of opportunity (not equivalence of outcomes). The essential criterion of methodologically sound research — and its primary function in social science — is that it is more objective than simply our opinions or our desire for something to be true. Rigid methodologies might hamper true discovery, but ideologies do an even greater disservice.

Some legitimate criticisms have been leveled at the positivistic research methods of the natural science—if they are the only ones considered respectable. Thus, a good case can be made for using a variety of methodologies: qualitative strategies, for example, sometime reveal a richness of information that cannot easily be obtained with more formal measurement procedures. Other important concerns have been raised regarding limitations of the scientific journal as the source of new information.

Luanna Meyer has frequently made the point that the impact of a good article in a popular magazine is often much greater than some arcane publication in a leading journal. Of course this is true, but the two are not incompatible, and, as she has advocated, we need additional not alternative sources of dissemination. This is becoming increasingly obvious with the rapid availability of information via the Internet. The problem with such information is its reliability and veracity is often suspect, lacking the ultimate standard of peer review by other experts using generally agreed upon standards of evidence.

The effects of such misinformation has become especially obvious in the case of the "rediscovery" of technologies that emerged in the early days of applied behavior analysis and that are now being touted as the answer in early education, particularly for all children with autism. Suddenly, once again, "discrete trial instruction," "fluency training," or "Lovaas techniques" are all the rage. Perhaps we went too far towards the direction of functional, holistic skills taught in natural contexts, and perhaps the basic principles of behavioral shaping are now less well-known to young teachers and psychologists. If so, that is regrettable and it will be necessary to ensure that effective methods are elaborated upon, not abandoned, as new information and new approaches are developed. Otherwise the field will consist simply of a series of fads, with the swinging pendulum producing apparently new approaches that longer memories will know have been around before.

Arthur Staats has argued that psychology (and by implication other social sciences and education in general) is a pre-paradigmatic science. That is to say there is no agreed-upon body of accepted knowledge whereby new discoveries build on old in a systematic manner. We are not unified as a science, and researchers in often very closely related areas do not cite each other or interface in mutually respectful ways. This further weakens the benefit of formal research as a foolproof way of resolving policy disputes, especially philosophical differences in approach or strategy. Professionals like to say glibly "that is an empirical question," but very often they are really value questions that cannot be answered by empirical research.

Consequently, a great deal of research seems to do little more than confirm what appears to be glaringly obvious. If we have a strong opinion about something or believe a particular approach or orientation to be the correct one, we are more likely to accept any supporting research findings as valid. If, on the other hand the research seems to contradict some firmly held presupposition, we are much more critical, examine the research methods more carefully, and look for alternative explanations for the findings.

Finally, we perhaps need to consider a little better who uses research findings — who are the real consumers? Of course other professionals are the primary audience and that is how it should be, if, as I have argued, one goal is to inspire innovation in practice. But research should be presented in a way that other interested persons — all stakeholders — can appreciate its significance. In recent years at some conferences I have been at, posters and oral presentations have ended up with a "take home message." This is a good idea. Having been nearly submerged in research findings, what is the main point that we need to grasp hold of and remember? More troublesome is when policy makers ignore what information is available and exercise their biases and personal judgments.

Once, when on one of the grant evaluation visits in Washington I described at the beginning of this article, one of the OSERS staff told me an interesting story. He was involved in the section on early education, funding some of the most prominent researchers in the country working with young children. As the research evidence mounted — in all those lovely final reports on his floor, as well as in the journals — this official started to push his superiors for more funding and more national efforts in early intervention. Then one day an Assistant Secretary for Education came rushing in to her senior managers and told them they had to immediately work on getting more early intervention to young children with severe disabilities. At last, thought my friend, she has been reading the research literature. Alas, that was not so. She had just got off the plane where she had been talking to the passenger next to her, a relative of a child with a disability, who told of the excellent progress the child was making in early education. And so it became national policy.

While this incident may be of dubious authenticity, the fact remains that research often does not influence policy relative to personal biases and ideologies of politicians and senior administrators. Often these beliefs are fine and the inspirational leadership of politicians such as John F. Kennedy, professionals such as Burton Blatt and Lou Brown, and many other pioneers who changed the shape of services for people with severe disabilities, was based on belief about civil rights, not data. But when there is a limited pie to be divided and support for one good idea may mean neglect

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Person Be Something Future?

BY THERESA REBHORN

The title of this article represents the first, original, independent writing that my daughter, Elise, did at age 12 when she was in 5th grade. The assignment --the first and only writing assignment she had received in her educational career -- was to write a sentence about anything she wanted.

Elise uses Speaking Dynamically Pro with a customized keyboard layout, auditory scanning, word prediction and a single switch that she accesses with her head. It took her about 45 minutes to write this statement, and she was very definite in her choices -- back spacing, spelling, and listening until she got exactly what she wanted. The question mark at the end resulted from my asking her, "Is this a telling sentence(.) or an asking sentence(?)?" Again, she was definite. This statement was a question in her mind; profound in its brevity and clarity.

Aside from the sentiment expressed, what is also remarkable about Elise's sentence is that, up to this point in her education at a special center, Elise had not really gotten much education at all. She and her classmates were not included in regular language arts classes. Even if her teachers had an expectation that Elise could be taught to read and write, they had no training or curriculum by which to teach her to do so.

Over the years of advocating for my daughter and other children, I learned this situation is not unique. Teacher preparation programs for special educators typically have not included content basics like reading, writing, and arithmetic. If there was a curriculum for children with more significant disabilities, it was a "functional" one.

Frustrated with the state of education for our children, I, and a handful of other parents, decided that "we were mad as hell and we weren't going to take it anymore." Bear in mind that, up to this point, our pleas for including our children in regular classes and adapting curriculum, as needed, had been ineffective. While our gut instincts told us that if the school would simply expose our children to regular education they were bound to learn more than they were learning in special classes, we had no evidence or proof to back us up. Faced with unwavering resistance from the school system, we put on our detective hats and went on a search.

Fortunately, in 1990, the Center for Literacy and Disability Studies at the University of North Carolina, Chapel Hill had been created. Originally devoted to literacy issues for individuals with severe speech and physical impairments, The Center's focus expanded because the need to get at literacy issues for individuals with all kinds of disabilities was so great. We learned about and began attending the Center's annual conferences in 1992. Here we heard about the Center's research projects and recommended instructional practices based upon that research. We took information back to our schools and the school system's administrators. We urged them to attend the conferences, to contact the Center themselves, to contract with them to provide in-service training.

For several years we tried individually and collectively to make something happen, all to no avail. We applied what we were learning to our children's lives outside of school. We found an experienced tutor and made small inroads based upon the work our children did with the tutor and provided documentation to the schools.

In the Spring of 1998, two of us had the opportunity to take our children to the Center for Independent Evaluations. Our thoughts were that with an evaluation, and child-specific recommendations from a credible source, perhaps we could get something concrete in their IEPs that the schools would have to provide. This strategy worked, sort of. Information from the evaluation was included in the IEP. More importantly, Elise's upcoming 6th grade special education teacher was willing and interested in learning more and in teaching Elise to read and write. At last, glorious, wonderful, baby steps.

Based upon Elise's and her teacher's experiences in 6th grade, the school system administrator for the Physical Disabilities Program attended the Center's 1999 conference. Next, our parent group decided to push the system a little more by offering to help pay to bring Dr. Karen Erickson up from the Center to do a two-day in-service for school system staff and parents in August, 1999. The parent group covered Dr. Erickson's fee; the school system covered her expenses, provided the setting, and helped to publicize the event. The next school year, Elise's 7th grade teacher and staff from the school district's technology department attended the Center's annual conference and began applying more recommended practices to Elise's instruction.

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One thing I do know. Because we became detectives, we found educators who believe, "All children can learn." These educators gave us the facts we needed to convince our school district. Advocacy alone didn't do it for our kids. It is only because we combined our advocacy skills with research-based knowledge that minds opened and positive change became a reality.

Research? Why Read This Stuff Anyhow?

BY MARY BETH PAUL

How has research influenced my quest to support my 11-year-old son? How has research strengthened the informal advocacy networks I am involved with, of other parents and those whose lives are affected by disability?

In the first and most dramatic sense, research played a part in my family's life as soon as my son Peter Ben was born in 1990. When we were told soon after that he had Down syndrome, my nurse said, "Don't read anything written about Down syndrome before 1985. 1987 is even better. There is so much more good information out now". How right she was! Getting up-to-date facts early on gave my husband Peter and I a jumpstart in advocating for our son.

I knew that early intervention practices were backed by research. I was aware of the early learning studies, of ways to help stimulate babies whose low muscle tone made it difficult to accomplish some motor milestones. I knew that there was research that encouraged use of signs with my baby, as it would help him communicate with less frustration until he could talk more fluently. The OT that worked with us mentioned some brain research that was showing the links between different kinds of movement and later communication-related tasks.

However, as my son went through his preschool years, he no longer continued to grow and develop as he had. Despite all the early learning activities, all the signing and singing, all the interventions, I saw my son retreat into a corner and flap his hands off to the side. I wasn't hearing any novel words after his initial use of signs and sign phrases. He didn't like to look at people and just didn't seem to have fun.

Turn the calendar ahead to 2002. Yesterday, I read a message from the owner of the Down syndrome-autism listserve that I joined three years ago. She posted the abstracts of five articles regarding the dual diagnosis of Down syndrome and autism. Over 200 families from around the world now have more supporting evidence to help unlock the mysteries of our kids who have autism coinciding with the genetics of Down syndrome.

Almost without exception, every time a new member of the Down syndrome-autism list finds us, she writes, "You have been a Godsend! A lifesaver! I was feeling so alone. No one would believe me when I said I suspected that my child (with Down syndrome) was also autistic. I was at my wit's end- my child's (teacher, doctor, speech therapist...) said I am (just in denial, contributing to my child's problem, not working hard enough, etc. etc.)"

Without all the researchers contributing to the expanding field about autism, the families I am describing would be less likely to insist that best practices for their children be put into place at school and at home. We now know how some people with autism think: in pictures, not in words, and about how much of a challenge it can be to communicate. Because our kids also have Down syndrome, too often ours kids' behaviors are chalked up to "He's just really low, and you are in denial", instead of "Let's explore other ways to help communication along."

Besides the list I described above, I have also belong to other disability-specific lists, an inclusion list, and the TASHUpdate list. I have had easy access not to just websites and web articles, but to books, ongoing studies, and sometimes the researchers themselves. The lists provide an important forum - to discuss what we have been reading, to critically question the information presented, to summarize lengthy or highly jargonized material in order to make it more user-friendly. At times it seems as though I am enrolled in an online university.

A few years ago, I was struggling with questions that seemed impossible to answer at the time. The idea of including my son in school was oh-so-appealing, the thought of "how on earth is this possible?" was another thing altogether. Fortunately there is now research that supports inclusive education, so it is more than just a "good idea". But I have been musing that without the actual know how behind the scenes, it could be next to impossible to include my son and many others.

I suspect that more people would be willing to read and then apply research if there were more opportunities to talk frankly with the authors. I would hope that researchers are open to such dialogue, and I propose that future TASH conferences continue to have sessions that bring together researchers, self-advocates, and advocates.

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Research? Why Read This Stuff Anyhow?

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This article is for the publication TASH *Connections*. While I have focused on how other parents, advocates, and I have used research for understanding and improving the quality of our children's lives, I don't want to leave the researchers out of this loop. I wonder if the researchers know who all reads their work, aside from when their publications are cited.

I have been learning to get and stay connected to others in order to continue "the good fight". One connection has been through doing formal and informal advocacy with some friends here in Ohio. Their invitation to attend TASH 2000 with them changed my life. The chance to sit and pick people's brains about some of the research issues mentioned here was very revealing and helpful. I loved the chance to dig deeper (for example, about "video self-modeling" and "what we have been learning about autism") and then put some of this information into practice when I got home. As important, the people I talked to were involved in advocacy in other ways besides research.

I also enjoyed the chance to ask, "What does this mean? Can you help me with XYZ? Tell me about other questions you are now working on. " Thus I have more ways to bring people to my son's IEP table; more ways to explore "How ?" and "Why"?

I suspect that more people would be willing to read and then apply research if there were more opportunities to talk frankly with the authors. I would hope that the researchers are open to such dialogue, and I propose that future TASH conferences have sessions that bring together researchers, self-advocates, and advocates. Only together can we all fight the good fight, armed with the knowledge that "Yes we CAN...here's how!"

Questions and comments concerning this article may be sent to Mary Beth Paul at <paul.3@osu.edu>

Why People with Disabilities Would Want to be Involved in Research

BY TIA NELIS

My name is Tia Nelis, and I work at the University of Illinois at Chicago for the Research and Training Center on Aging and Developmental Disabilities. I work as a self-advocacy specialist. I want to talk about why I think people with disabilities should get involved in using research for advocacy.

I believe that people with disabilities could use the research to help them advocate for what they want. For example, when you go to testify sometimes legislators want numbers to back things up. You could use available and emerging research to help make your point.

I know sometimes people don't like research because they feel it is done in the wrong way, or they had a bad experience with the person doing it. Or they have concerns that the research will not be used, that after it is done it just sits on a shelf.

We should work to make sure that the research being done is important and is being done in a way that people can use it. To do this, people with disabilities need to be a part of research projects. They need to have the opportunity to voice their opinions, give suggestions, tell researchers what they think, and share ideas with them. Sometimes we need to remind people about how to include people with disabilities, and how the research they are doing could affect your life and the lives of others.

If research is done in a way that it is a true partnership between the researcher and the people being studied, and if research is done so people can understand and use it, I think more people would get involved. It is important for people to get involved so they can help with the writing and so they can understand what the research is about. Involving people with disabilities in research helps to make sure that the research being done is good, and it is going to help people and not make things worse. People with disabilities need to be there to advocate for what is important, and give researchers ideas about what to study and how to present their research so it will be used.

Many good things come out of research that help people and makes things better for their lives. I think people with disabilities should get involved in the kind of research that is going to make a difference so that there will be an understanding about the roles that people with disabilities can play, and so they have the supports they may need to be actively involved in the research. There needs to be respect by and for people with disabilities and researchers and the feeling of a true partnership.

By involving people with disabilities in research, more people will come to understand what it is about and the quality of the research will be increased by working together. People with disabilities could also learn new things by being a part of research projects. If all the things that are mentioned above are done and you want to be involved in research, then go for it. You *can* make a difference!

Tia Nelis is a member of the Executive Board of TASH.

Research, Advocacy, and the Making of Public Policy

BY LYLE ROMER, ALICE PORTER, AND MARY RICHARDSON

The making of public policy is often likened to the making of sausage — people are advised if they think they like either, don't watch them being made. Public policy is a complicated, chaotic mix of society's ethics, values, deeply held beliefs, and to a lesser extent, actual fact.

The making of disability policy is particularly complex because it incorporates social views, knowledge as well as misconceptions about how people become disabled, and the issue of societal responsibility for their well-being. Over time, research has supplanted many of the myths and unfounded beliefs about disability with empirical evidence about the cause, likely course, and probable impact of a wide range of chronic conditions and disabilities. But policy makers are first attuned to the perspectives of people who feel strongly about an issue, regardless of whether they are sadly lacking in current knowledge.

Part of the problem is the lack of connection between the policy makers and the "fact makers" or researchers. Often seen as isolated and existing in the ivory tower, researchers are more likely to communicate their work among themselves than with the broader public. Thus, those who influence policy making -- advocates and special interest groups -- must specifically seek out scientists and sift through their work. Advocates have the opportunity, as well as the responsibility, to interpret research findings once they find them.

The University of Washington Center for Disability Policy and Research (CDPR) has since 1992 generated research findings that can play a significant role in state policy making for people with developmental disabilities. CDPR seeks to involve members of the disability community to assure that the research is appropriately shaped by the core principles and values established within the community. This article will describe the results of one such partnership: CDPR's three evaluations of Washington's Family Support Opportunity Program.

Research, advocates, and one program

Family support programs have become an integral component of all states' services and supports to people with developmental disabilities and their families. But most states still maintain waiting lists for family support services, in part because of budget constraints.

In 1996, Washington State's family support program provided funds considerably greater than the national average, but enrolled a much smaller share of families. The Division of Developmental Disabilities (DDD) enrolled about 3,500 families in family support, and spending on the program represented 6.1% of the DDD community budget compared with a national average that year of 3.3% of the community budgets in other states. Washington spent $6,759 a year per family, compared with a national average of only $1,875. But in that same year, Washington enrolled only 39.4 families for every 100,000 people in the state- slightly more than half the national average of 76.4 families.

This created a budget dilemma for the state: how to extend the benefits of its family support program in an environment where little additional funding could be committed. The Division of Developmental Disabilities turned to advocacy groups for their assistance in designing a new family support program. The Family Support Task Force, consisting primarily of parents of children with disabilities living in their families' homes, guided design and implementation of the new program. Most of the task force members desired to see five general components in the new program: respite and in-home supports; access to medical services; information about other services available to families; flexible funds for families to use to purchase needed services and materials; and access to other resources (not funded by DDD) in families' communities.

With this input from families, DDD proposed to the task force a new program that would combine short-term assistance in the form of cash reimbursements to families, in-home support through Medicaid personal care, and access to information about other services and community resources through the newly developed community guide initiative. Cash reimbursements would be made available to families for most materials and services for up to $900 per year (since raised to $1,300 per year). Family members with disabilities would be placed under the home and community-based waiver to obtain Medicaid coverage and Medicaid personal care.

Finally, each family would be given access to a community guide, a person from their own community with extensive knowledge of both disability issues and generic resources. The community guides would meet with each family that desired their services to determine what assistance the families deemed most important. The community guide would then work with families to locate information that would connect those families to needed supports in their communities. Community guides would receive up to $200 per family, per year. (For a fuller description of the community guide initiative, see Romer, Richardson, Nahom, Aigbe, and Porter (In Press).

After approval by the Family Support Task Force, DDD offered the new Family Support Opportunity Program (FSO) to families as a pilot program. As part of the pilot process, DDD contracted with the Center for Disability Policy and Research (CDPR) to conduct a review.

After surveying 94 of the initial 277 families to enroll in the new program and interviewing another 40, CDPR concluded that

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while the program had several areas where it needed to clarify its goals and methods, overall it showed great promise for addressing the issues most critical to families. Among areas that seemed well received by families were the short-term assistance funds, the in-home support of Medicaid personal care, and the services of the community guides. But CDPR also found that families felt the program lacked clarity in its goals and just what services were available. After review by the Family Support Task Force and the DDD, the Division fully implemented the program statewide while paying particular attention to providing families with better information about services and clarifying the role of community guides.

Two years later, the Division for Developmental Disabilities once again asked CDPR to evaluate the progress of the Family Support Opportunity program. The results this time were quite gratifying; families reported a distinct improvement in both the program's approach and outcomes. They were especially pleased with the community guides, and data collected from 312 families using the guides showed that they felt connected to their communities, that their situations were better understood by FSO, their emotional or physical well-being was improved, and it was easier to care for the family member with disabilities. Furthermore, families indicated high satisfaction with finding service providers, the clarity of information provided, and their role in defining what supports they wanted most. Based on this feedback, DDD once again made modifications to the FSO program. Notably, DDD emphasized the role of the community guide in assisting families to locate appropriate community options for desired supports by refining community guide training curricula and, in three of the state's six social and health services regions, contracting with outside agencies to recruit and train community guides.

In a third evaluation of FSO conducted in 2001, CDPR received surveys from 925 families about their experiences with the FSO. The results showed continued improvement in the program. Family ratings of how well the program met their needs were all higher than those obtained in the 1999 review. Due in large part to the continued efforts of three groups-DDD, the Family Support Task Force, and CDPR-the FSO program has been able to address the desired need for support of more than 6,000 families in Washington. Families consistently give the FSO high marks, and more families are enrolled than would have ever been possible given the budget of the old family support program.

The researcher-advocate partnership
The Family Support Opportunity experience shows the benefits of researchers, policy makers and consumers working together to influence public policy. Another such partnership has effectively influenced mental health services. Advocates for the mentally ill often have identified research on mental illness as their highest priority, calling for substantial government investment. Consequently, mental health researchers have considerable incentives to work closely with the advocacy community, both to assist in interpretation and application of findings and to guide the direction of future research.

There are reasons why other advocates and researchers have yet to achieve such a partnership for disability policy. Disability advocates represent a broad range of organizations, reflecting the variety of factors and conditions contributing to disability. There is no common voice, so it is difficult to coalesce around common issues as the mental health advocacy community has done. In fact, many in the disability community perceive investment in research as diverting resources that are needed to provide services to people with disabilities. In fact, further research and attention to disability issues would benefit all involved.

Four standards should guide this partnership:

1. Research, by definition, reflects social values. The disability community has worked very hard to define the fundamental values driving services and policy. Disability research needs to be predicated on this value base.

2. Advocacy organizations accept the responsibility to influence public policy in a way that will guide the research agenda and promote appropriate investment in research.

3. Scientists have make the commitment to communicate their research and its findings to a broad public audience, including those with disabilities and those who advocate for them.

4. Advocates and scientists agree to cooperate to ensure that public supports and services are truly available to those who need them, regardless of language, culture, or other potentially limiting factors.

Challenges to assuring equal access, independence, and full community integration for persons with disabilities remain significant and, in a retreating economy, they continue to grow. Meeting these challenges will take hard work on the part of all communities vested in making changes, including research. It is incumbent upon the advocacy communities to reach out and support disability research, whether aimed at changing individual situations or broad public policies. And it is incumbent upon the research community to listen, involve advocates and consumers in shaping the research agenda, and assure that findings and results are communicated widely and effectively.

Reference

Romer, L. T., Richardson, M. L., Nahom, D., Aigbe, E., & Porter, A. (In Press). Providing family support through community guides. *Mental Retardation.*

Lyle Romer, Alice Porter and Mary Richardson are with the Center for Disability Policy and Research, University of Washington, Seattle. Comments about this article may be sent to Lyle Romer at <lyleromer@cs.com>

Why Bother to Prove What I Already Know?

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of another equally fine idea, then research data is one — not the only — source of information whereby effective choices can be made. This starts at the clinical level and continues all the way through to major national policies. Let us keep it coming, let us keep it funded, and let us continue healthy debate on the value of different methods and standards of usable knowledge.

Ian M. Evans, Ph.D, is in the School of Psychology at Massey University in Palmerston North, New Zealand.

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Person Be Something Future?

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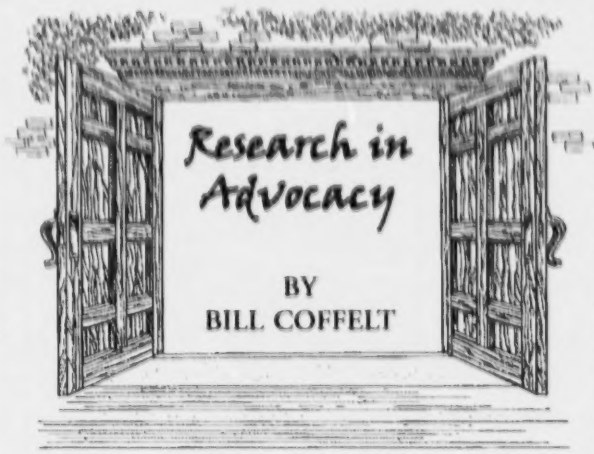
Something else happened between 6th and 7th grade that bears mention, as well. The regulations for implementing IDEA '97 were issued. For our school system, IDEA '97 was a necessary reminder and directive that children with disabilities should be educated in their neighborhood schools and provided maximum access to the general education curriculum. We also had a positive change in leadership in our school district that, along with IDEA '97, resulted in a district-wide initiative for inclusive education in neighborhood schools. As a result, Elise's lost opportunities were found again in middle school!

The following school year, the PD administrator, with assistance from Elise's teacher, provided an in-service for all the PD teachers in the district and provided staff with copies of Classrooms That Work: They Can All Read and Write by Patricia M. Cunningham and Richard L. Allington. This was a real breakthrough, with the school system demonstrating "buy-in" that kids like ours could be taught to read and write, and providing teachers with some tools to use.
So, after the poverty of her elementary education, for 2 1/2 years now Elise and other students have been receiving some research-based instruction in reading and writing. Elise has also been getting real instruction in other subjects and is in four regular education classes. Is it everything it should be? No. Does it fulfill the vision of inclusive education I had when Elise was entering kindergarten? No. Is it better than it was? Absolutely. However, the school system needs to do more in the way of providing and supporting staff development. To my knowledge, no other trainings have been done since September 2000.

One thing I do know. Because we became detectives, we found educators who believe, "All children can learn." These educators gave us the facts we needed to convince our school district. Advocacy alone didn't do it for our kids. It is only because we combined our advocacy skills with research-based knowledge that minds opened and positive change became a reality.

Theresa Rebhorn is a Senior Writer/Editor with National Information Center for Children and Youth with Disabilities.



"Needed: Copies of studies or papers written on the comparative costs of various residential and/or support services for people with mental retardation and developmental disabilities. Send copies to: [Omitted for privacy purposes.]"

The above request on the Voice of the Retarded (VOR) home page <http://www.vor.net> is as good as any reason why research is important for advocates who support community inclusion. VOR is the only national organization that continues to support institutions and congregate facilities as residential options for individuals with developmental disabilities. VOR and other parent organizations that advocate for institutions often look for research that supports their claim that some people cannot be served and supported in the community.

For example, the parent organization, Texans Supporting State Schools (TSSS) points proudly to research showing that "Texas's funding per resident of state schools is 30% below the national average for congregate facilities. Only four states fund their large facilities at a lower level."

Research by David Strauss of the University of California at Riverside showing a higher mortality rate in the community[1] as compared to California's public institutions brought movement out of the institutions almost to a standstill when used by those who oppose community for all, such as state hospital parent groups and public employee unions. The San Francisco Chronicle ran a series of over 50 articles based on Dr. Strauss's research. Fortunately, Dr. Strauss's research has not been replicated and the issue was put into perspective when the journal, Mental Retardation, devoted an entire issue to mortality research (Vol. 36 No. 5 October 1998).

[1]This research was controversial. The findings were not replicated. For a full discussion of this and related research on California mortality the reader is directed to the October 1998 issue of *Mental Retardation (vol. 36), #5.*

My own use of research in support of advocacy began in the summer of 1989 shortly after we placed our eleven-year-old son, Billy, in Sonoma Developmental Center, the largest public institution in the United States. We made what turned out to be a disastrous decision because the system was unable to offer more viable options, such as a small group home for children with severe behavior issues, in our home community.

Billy resided on a ward called the Oaks Unit with 25 other children ranging in age from eight to eighteen, who were ambulatory and had behavior issues. It wasn't long before Billy was hurt and required hospitalization. Because things were so bad for the children at Sonoma, I wrote a letter to the Deputy Director of the California Department of Developmental Services and asked if we lived in any other state, would things be so bad for our family and Billy. His reply was that California's developmental centers were federally certified, state licensed, and that California was the only state that went the extra mile by voluntarily seeking private accreditation from the Accreditation Council on Developmental Disabilities. His attempt to assure me that I could find no better services in any other state was so patently false, that I went on a quest of my own. It didn't take long to find there were some states doing some things better than California and there were some states doing some things worse. But as a staff person at the President's Commission on Mental Retardation told me, "Things are bad all over."

Thus lies the importance of research. Why reinvent the wheel? If some state has figured out an innovative way of supporting someone, let's find out and copy it. This, in my view, is what led to supported living, alternative foster care, full inclusion, person-centered planning, and self-determination.

As I remember, my early quest led me to two entities that were doing the kind of research I needed to advocate the kind of changes I felt we needed in California — David Braddock's Department of Disability and Human Development at the University of Illinois at Chicago, which publishes states' fiscal efforts in State of the States <http://www.uic.edu/depts/idhd/StateoftheStates/home.htm> and the Institute on Community Integration in Minnesota, which published a report on the attitudes of parents before and after their children left institutions. More recently, the Institute's Research and Training Center on Community Living <http://rtc.umn.edu/> has published Residential Services for Persons with Developmental Disabilities: Status and Trends. The reports from these research centers have proven invaluable in my advocacy over the years.

...Thus lies the importance of research. Why reinvent the wheel? If some state has figured out an innovative way of supporting someone, let's find out and copy it. This, in my view, is what led to supported living, alternative foster care, full inclusion, person-centered planning, and self-determination.

Shortly after placing Billy, I joined with other parents and formed the Oaks Group.

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Research in Advocacy

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Our goal was to improve conditions at Sonoma Developmental Center and get our kids out. Our biggest accomplishment was suing the State of California in what was known as Coffelt v. DDS. The settlement agreement resulted in the movement of over 2,000 individuals out of California's state institutions into community living arrangements.

> *The bottom line is as long as there are people out there using research to promote segregating people in institutions that devalue them, community advocates are going to have to seek out research that demonstrates that people living in their home communities with friends, family, and neighbors is not only the preferred choice of people with disabilities, but it is more cost effective than housing people in institutions.*

A major component of the settlement agreement was a means to track the movement of the people and survey how they were doing. The Center on Outcome Analysis (COA), directed by Dr. James Conroy, was selected as an independent contractor by both the plaintiffs and defendants to survey those leaving the institutions and their families and determine whether they were better off, were their families satisfied, and was the state meeting its commitment.

As an advocate and parent of the lead plaintiff in the lawsuit, I followed Dr. Conroy's research carefully. During the four years of the settlement, over seventeen reports were filed. Obviously, I was gratified that the reports showed the movement was an overwhelming success.

After we got our kids out and into community living arrangements, the Oaks Group disbanded. We reformed in 1997, when the Strauss research was published, in an effort to combat the work that was being undone by the San Francisco Chronicle series based on Dr. Strauss's research and its use by those who want to keep institutions. We started a website -- http://oaksgroup.org -- that has been acclaimed as a source of information and research.

Last year, the Center on Human Policy reissued the Community Imperative, which led to my starting the California Developmental Disabilities Community Imperative (CAL-DDCOMMIMP) discussion group <http://groups.yahoo.com/group/CAL-DDCOMMIMP>, acclaimed for its files and bookmark sections that lead to research that supports community advocacy.

Finally, last year I helped start the National Coalition on Self-Determination <http://www.oaksgroup.org/nconsd>, the only national partnership of persons with disabilities, parents, and family members that work to promote federal policy that supports the principles of self-determination and the values of the Community Imperative.

As a long time member of TASH, I looked in my past issues of JASH for research on self-determination. I quickly found, not surprisingly, that almost an entire issue had been devoted to self-determination (Volume 23, Number 1, Spring 1998).

So the bottom line is as long as there are people out there using research to promote segregating people in institutions that devalue them, community advocates are going to have to seek out research that demonstrates that people living in their home communities with friends, family, and neighbors is not only the preferred choice of people with disabilities, but it is more cost effective than housing people in institutions.

Bill Coffelt is Co-Chair (Parent Representative) of the National Coalition on Self-Determination. Comments regarding this article may be directed to Mr. Coffelt via the National Coalition's web site, <http://www.oaksgroup.org/nconsd>

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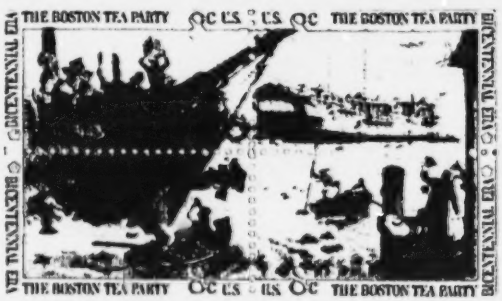
2002 TASH International Conference

Our Quest: Opportunity, Equality, Justice

December 11-14th



The revolutionary idea that individuals should have the opportunity for a fulfilling life of their own choosing was born long before the Revolution. Our earliest leaders understood that freedom and choice are the cornerstones of quality lives, and the key to fulfillment and success for all.

Some say it's idealism. We say it's our right, our dream, *Our Quest: Opportunity, Equality, and Justice.* Though certainly not a revolutionary idea anymore, far too many people labeled with disabilities are still struggling each and everyday for the right to life, liberty, and the pursuit of happiness.

The TASH Conference is the modern day "Tea Party." Much like this early movement, the TASH Conference mobilizes vast numbers of people, linking folks from around the world together in a common experience of mass popular insistence - Equality, Justice and Opportunity for ALL! Just as with the "tea party," the electrifying information and energy generated at the conference spreads, others follow the example and return home to stage similar acts of resistance and insistence of their own.

Over 2,500 patriots of the disability movement will gather at the TASH Conference in Boston on December 11th to share strategies, renew commitment, and create a synergy surpassed by none. BE THERE.

Location

Sheraton Boston Hotel
Prudential Center
39 Dalton Street
Boston, Massachusetts 02199
Direct Phone/Reservations:
(617) 236-2000
Fax: (617) 236-1702
Toll-Free Reservations call 1-888-625-5144 in the U.S. or Canada

The Sheraton has confirmed the following group rate, available to TASH Conference attendees:

Single Occupancy (one person) $145.00
Double Occupancy (two people) $153.00
$20.00 per night for each additional person
Applicable Boston Sales Tax - 12.45%

Conference Rates*

Category	TASH Member Current or Joining Now	Non-Member
Individual TASH Member	$239	$371
Student	$149	$239
Family Member or Individual with a disability	$59	$104
Thurs or Fri only	$149	$199
Saturday Only	$49	$79
Preconference Workshops	$55	$85

*These rates will be in effect for registrations received prior to November 29, 2002. A $50 late fee/on-site fee will be added to all rates after that date.

The Sheraton will accept reservations under the TASH block at the above rate, subject to availability. After the TASH block has been sold out, or after Monday , November 11, 2002, the rate may be higher. The TASH Conference is a well-attended, popular event - so make your reservations early!

Official Airline

US Airways has been designated as the official carrier for the attendees of the TASH Annual Conference. US Airways agrees to offer an exclusive low fare for TASH Attendees. This special fare will be offered at a 7% discount off First or Envoy Class and any published US Airways published promotional round trip fare. A 12% discount off the unrestricted "Y" or B8YS/B4US fares will apply with no advance reservations and ticketing required. Plan ahead and receive a 17% additional discount by ticketing 60 days or more prior to departure.

To obtain these discounts, book online with usairways.com using Meeting ID MTG000448.

If you do not have internet access or would prefer to make reservations over the phone, you or your travel consultant must call US Airways Group and Meeting Reservation Office toll free at 877-874-7687between 8:00 AM and 9:30 PM Eastern Time. Refer to GOLD FILE NO. 24622391.

2002 TASH Awards

It's time once again to submit TASH Award Applications!

This year at the annual conference TASH will again confer the Alice Hayden, Thomas Haring and the Image Awards. This is the second year for the Image Awards, which honor the groundbreaking and exemplary work of individuals and companies to create and promote positive images of people with disabilities.

This is your chance to honor such accomplishments with official recognition. Please take the time to submit an application. Awards will be conferred as part of the TASH Annual Conference to be held in Boston, December 11-14th. Award applications will be accepted through August 1, 2002. Please be sure to indicate for which award you are applying on the application, and submit all required documents or information requested for that award.

2002 Alice H. Hayden Award

This $500 cash award will be presented to a doctoral student enrolled in a program in education or a related field and who demonstrates potential for leadership in teaching, scholarship, and service on behalf of people with significant disabilities. The individual needs to have demonstrated a continuing desire in working in partnership with people with disabilities.

2002 Image Awards

This award honors presentations in print, film or other media which promote the positive images of people with significant disabilities in all aspects of community life. Criteria for selection include:

- Emphasis on inclusion or civil rights aspects of issues or stories
- Supports self-determination and or independent living philosophy
- Promotes empowerment
- Values the civic participation of individuals with disabilities
- Contributes to the shaping of positive images and helps to eliminate stereotypes by accurately portraying people with disabilities
- People with disabilities are the primary source(s) of information
- Accessible (must be available in alternate format such as captioned or large print)
- Portrays diversity

2002 Thomas G. Haring Award for Research

This $1000 cash award is presented to promote research and scholarly activity in the field of significant disabilities. The award will be presented to the author(s) of a study of particular significance that was published in JASH within the two years prior to the annual conference. The study will have demonstrated scientific merit, and have made an important contribution to the disability field.

2002 TASH Award Application

- Applications due August 1, 2002

How to Apply:

(1) Complete this application form - front and back - as fully as possible.

(2) Attach a brief narrative discussing why the nomination is being made. Please see the other side of this form for a list of supporting information and materials that must be submitted for the particular award you choose below.

3) Please indicate for which award you are applying. **Check only one award.**

- ❒ Alice H. Hayden Award
- ❒ Positive Images Award
- ❒ The Thomas G. Haring Award for Research

(4) To be considered, the original completed application and supporting materials must be received in the TASH central office no later than August 1, 2002. Send to:

Awards Committee
TASH
29 West Susquehanna Avenue
Suite 210
Baltimore, MD 21204

Person or Team Being Nominated:

Name of the Individual: _____

Street Address: _____

City: _____

State/Province: _____ **Country:** _____

Zip/Postal Code: _____

Daytime Telephone: (___) _____

Evening Telephone: (___) _____

Is this individual(s) a member of TASH?
❒ **Yes** ❒ **No**

Name of team members (more room on reverse side) _____

Street Address: _____

City: _____

State/Province: _____ **Country:** _____

Zip/Postal Code: _____

Daytime Telephone: (___) _____

Evening Telephone: (___) _____

Is this individual(s) a member of TASH?
❒ **Yes** ❒ **No**

Person Making the Nomination:

Name: _____

Relationship to the team/person: _____

Street Address: _____ **City:** _____

State/Province: _____ **Country** _____ **Zip/Postal Code:** _____

Daytime Telephone: (___) _____ **Evening Telephone:** _____

FAX:(___) _____ **E-mail:** _____

Please provide as much information as possible about the persons who are part of this team. Please use additional paper if necessary.

Name of Team Member:

_____

Organization (if applicable):_____

Street Address:_____

City:_____

State/Province:_____ **Country:**_____

Zip/Postal Code:_____

Daytime Telephone: (___)_____

Evening Telephone: (___)_____

Is this individual(s) a member of TASH?
❒ Yes ❒ No

***

Name of Team Member:

_____

Organization (if applicable):_____

Street Address:_____

City:_____

State/Province:_____ **Country:**_____

Zip/Postal Code:_____

Daytime Telephone: (___)_____

Evening Telephone: (___)_____

Is this individual(s) a member of TASH?
❒ Yes ❒ No

***

Name of Team Member:

_____

Organization (if applicable):_____

Street Address:_____

City:_____

State/Province:_____ **Country:**_____

Zip/Postal Code:_____

Daytime Telephone: (___)_____

Evening Telephone: (___)_____

Is this individual(s) a member of TASH?
❒ Yes ❒ No

***

Media Contacts

Please provide on a separate sheet of paper, the names and addresses of local radio, television, or newspaper outlets that would be interested in covering the presentation of the award.

Award Application Requirements

Alice H. Hayden Award:

1. Attach a curriculum vitae outlining your history of: a) higher education (including major, minor, degree, date of completion); b) employment (including dates, duties, name of supervisor); c) research and publications.
2. Also attach 500-1000 word essay which describes: a) your current work on behalf of individuals with severe disabilities; b) your educational and professional objectives.
3. Attach at least three (3) letters which support the nomination. These letters should be from professors who are familiar with your qualifications. The letters should present specific data or anecdotal information which convey an accurate picture of your current achievements and potential for significant contributions to the field.

Image Award:

1. Please provide a brief description of the project, including the medium used (ie: radio, television, newspaper, magazine).
2. If the nomination is in the film category, please indicate the length of the video in minutes.
3. Attach at least one copy of the nominee's work, or of the specific project being nominated. If the nomination is in the print category, the submission must be neat and legible. If the nomination is in the film category, a video copy (VHS 1/2") must accompany the nomination. The submitted work must be sufficient to demonstrate that the work meets or exceeds the criteria for the award.

Thomas G. Haring Award for Research:

1. To be eligible for the award, the authors' manuscript must have been published in JASH within the two year period prior to the conference. The senior author must agree to be present at the upcoming conference, and to present the contents of the paper as a conference session.
2. To make a nomination, submit a letter which references the article, and addresses the study's significance, scientific merit, and the importance of its contribution to the disability field.

Permission to show video submittals:

If the nomination is in the film category, please complete and sign the following to hereby grant permission to TASH to show:

(Title)_____,

for, but not restricted to, promotion of the TASH Media Awards and the TASH Annual Conference. Similarly, as it applies to the promotion of the TASH Awards and the TASH Conference, the producers waive any monetary compensation .

Signature:_____

ACTION RESEARCH AT THE CENTER ON HUMAN POLICY

BY STEVE TAYLOR and PAM WALKER

There is a long tradition of "action research" linked to qualitative studies in the social sciences. Since its founding in 1971, the Center on Human Policy has engaged in such research. For example, on the basis of research at institutions and other residential settings for people labeled with mental retardation, the Center on Human Policy has prepared in-depth descriptive reports of institutional abuse and neglect for federal courts, the popular media, policy makers, and organizations composed of people with disabilities and their families (Taylor & Bogdan, 1998).

This article describes action research focused on residential settings for people with developmental disability labels. First, it discusses a rationale for such research and some general components of the research; next, one example of action research is provided.

Research in Residential Settings

Action research in residential settings may be undertaken based on interest in finding out what the experience is for people with disabilities in a given setting, or in response to a concern raised by people with disabilities, family members, human service workers, or other allies. Agencies that provide services and receive public funds are typically required to evaluate themselves. However, such formal evaluation is not a substitute for research or monitoring by independent advocacy or consumer groups. Too often, in agency evaluation, the focus is on bureaucratic criteria rather than quality issues. Or, formal evaluation may consist largely of a "paper audit," or an inspection of written policies and procedures. Thus, it cannot be left up to states to adequately monitor the quality of services.

In the process of conducting research in residential settings, you can educate yourself about problems that exist and what needs to be changed. There are no hard and fast rules of such research, though there are some more or less effective strategies (Taylor, 1980).

❖ *Collecting public information:* In examining residential settings, it might be useful to review various reports (e.g., inspection reports) and collect various types of information (e.g., state expenditures in institutions versus community services), depending on the focus of your research efforts. Under the Freedom of Information Act, you have a right to review and obtain certain documents and information compiled by federal agencies. Certain useful ones may be state plans and Medicaid deficiency reports; service system data (e.g., expenditures, for example)

❖ *Collecting descriptive information:* Participant observation is one research technique for studying social settings; it involves observation and recording of detailed field notes. Modified versions of this technique can be used for observing residential settings. Descriptive reports are prepared, based on careful observation and detailed description of the conditions and practices in residential settings.

No research is values free; researchers cannot avoid taking sides (Becker, 1966-1967; Mills, 1959). Qualitative research can be a very effective tool to bring out the perspectives of people whose voices have not been heard in the past—for example, the experiences of people with severe developmental disabilities living within residential service settings.

Descriptive reports can also be based on a team observation approach. This requires more planning and coordination. Information gathered through such research can be used in a variety of ways: to help select priorities for advocacy, to identify conditions or practices which need to be changed immediately, to challenge official data or statistics, or to prepare a report on services in your state or community.

Action Research Example

This section describes an action research study undertaken by staff at the Center on Human Policy and the Center's Advocacy Board in 1988. It briefly explains the context within which the research was undertaken, and gives a summary of some of the issues and recommendations contained within the report.

Based initially on a concern raised by a relative of a person with a developmental disability, the Center on Human Policy and its Advocacy Board decided to examine the use of room and board and adult homes for people with developmental disability and psychiatric labels in Onondaga County. In order to do this, the Center on Human Policy and the Advocacy Board took the following steps: meeting with local officials to obtain their perspectives; visiting various room and board and adult homes; and writing a report describing what was observed, and highlighting specific critical issues and recommendations to address these issues.

The Center's report received widespread publicity in Central New York. In an editorial published in October 1988 the *Syracuse Herald-Journal* condemned the placement of people with developmental disabilities in boarding homes based on the Center's report: "Shame: We're not helping those who are most in need of our help."

As a result of the visits, and based on current trends in supporting people with developmental disabilities and mental health diagnoses in the community, the following issues were identified:

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ACTION RESEARCH AT THE CENTER ON HUMAN POLICY

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1. Size: Both the room and board and the adult homes are extremely large, considering emerging standards for the size of community residential programs. They range in size from 9-16 people for the room and board homes and from 16-173 for the adult homes. As such, they are inappropriate places for people with disabilities to live, regardless of the conditions in the homes. Proprietors told us that regulations are "causing" larger and larger adult homes to be established, because it is economically not feasible to operate a small home and make a profit. One proprietor told us of plans by other companies for 200-300 bed adult homes for elderly people in the county.

2. Quality: In the room and board homes, which are not regulated by any governmental agency, quality concerns extended to basic issues such as cleanliness. In the adult homes, people's quality of life was the major issue. In both types of settings, many of the people appear to be inactive during the day (e.g., sleeping, sitting around, wandering the halls, etc.) rather than out in the community engaged in meaningful activities such as work. Mealtimes are extremely regimented, and access to food at other times is severely restricted, except in one place.

Expectations of the people living in these homes are apparently very low, both on the part of the referring agency and the homes. People are not expected to work, to be a part of the community, to cook or clean up for themselves, or to take responsibility for themselves. The people in the homes are not provided with training or assistance to gain these skills, so they may lose the skills they once had.

3. Lack of regulation/oversight of room and board homes. Because the room and board homes are unregulated and unmonitored, poor conditions are allowed to persist. No public agency accepts responsibility for the quality of life and well-being of people placed there.

4. Lack of appropriate alternatives to these settings. In discussions with officials and staff, we have been told repeatedly that both the room and board and adult facilities are "better than the streets"; in other words, that these facilities meet some needs and, without them, people would be homeless and without regular meals. We also have been told that some family members and residents of the facilities themselves choose the adult and room and board facilities over the available alternatives (homelessness or institutionalization).

We do not find this defense of room and board and adult facilities compelling and believe that to view them in terms of their superiority to homelessness is to miss the point. We—and, we believe, a significant sector of this community—have higher standards for services for people with developmental disabilities and mental health diagnoses and, indeed, for elderly people and those with other needs. If the problem is a lack of alternatives—affordable and decent housing and a range of support services—then the solution is to develop those alternatives, rather than to attempt to justify inappropriate facilities.

Recommendations

1. Referrals to these homes should stop. As long as the service agencies see these facilities as an acceptable option, other alternatives will not be developed.

2. Human service agencies should review each person they have placed in one of these facilities and develop an alternative placement plan for each. It is essential that people themselves and, if appropriate, their families, be involved in the development of these plans and be presented with positive options.

3. Human service agencies, in conjunction with the county, should create or obtain appropriate alternatives for people with developmental disability or psychiatric labels who are now referred to these homes.

4. Service agencies should investigate a change in the way the state SSI supplement is awarded so it is not so restrictive of people's options. The laws creating the state SSI supplement need to be reviewed and revamped as one of many ways to eliminate disincentives for people to move out of group care and into homes of their own where they can receive the supports they need.

5. A broad community coalition such as the coalition for health and welfare should take a stand on these issues and look at ways of resolving the problems that force people into these homes and to tackle the policy issues on both the local and state levels.

Conclusion

In addition to written reports, there are a number of different advocacy strategies that can be taken based on research findings. Selecting these strategies based on the issues that are uncovered will be most effective in creating change. These could include: arranging meetings with service agencies to discuss findings and recommendations based on these findings; identifying gaps in the service system and convening groups of service system representatives, families, people with disabilities, and other allies to advocate for change in the way services as a whole are offered; arranging for media coverage; offering legislative testimony; and sponsoring public forums. Such efforts can be strengthened through building coalitions; for example, in order to address issues related to support for people in their own homes versus institutions and nursing homes, the Center on Human Policy has organized a diverse coalition, including people with a variety of disability labels, people who are elderly, and others concerned with promoting home life for all (Taylor, 1999).

Over the years, the Center on Human Policy's research and advocacy efforts have always been closely linked to each other, and rooted in the Center's core value of inclusion for all. No research is values free; researchers cannot avoid taking sides (Becker, 1966-1967; Mills, 1959). Qualita-

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ACTION RESEARCH AT THE CENTER ON HUMAN POLICY

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tive research can be a very effective tool to bring out the perspectives of people whose voices have not been heard in the past—for example, the experiences of people with severe developmental disabilities living within residential service settings. For Mills, the role of the sociologist (qualitative researcher) is to help people translate their "personal troubles" into "public issues." Thus, such research related to residential settings for adults with developmental disabilities, for example, can, serve as the basis for further efforts to help improve the quality of services, and ultimately, the quality of life of people with severe disabilities.

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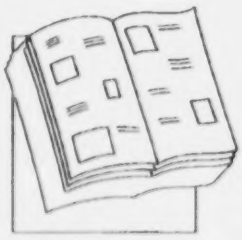

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My personal musings on research & data based advocacy

BY DONNA MARTIN

I first used research when I entered my son's segregated school in the Saddleback School District in Orange County, California. It was 13 years ago and he was in preschool. The school was considered a state of the art building that housed and served students with moderate to severe cognitive disabilities from age 3 to 22. It was there I came armed with the journal articles of best research, which showed that this new idea of having students taught with their peers had some empirical basis. I came by these articles by virtue of being a university student in special education: some were course readings and others found information on my part to be used in the IEP meeting to show I wasn't some crazy mother asking for some outland-ish program for inclusion.

I even brought in the journals themselves, as well as a list of footnotes and bibliography for further information to show the staff and the District Special Education Director chairing my IEP that I really knew what I was talking about. It was there that each school system participant decreed that it was still, nonetheless, a ridiculous and unsup-portable possibility for my 3-year-old son to be taught with his non-disabled peers. Even the concept of taking him along with the class on their community based instruction (CBI) outings to the local library to join in with the community preschool reading period was too far out there, that going bowling was a much better use of his preschool instructional time.

There were two significant comments to me that came from the IEP meetings by the Director of Special Education. The first was to share how impressed she was with my research capabilities and asked if I'd like to start working for the district as they needed special education teachers, and having my credential wouldn't be an essential or immediate criteria.

The other most unforgettable comment from her was that, while this data and information was nice, I had to be aware of what reality outside the walls of empirical study was. She assured me that the professors and gurus of academia truly had no real clue about life in the trenches of special education and school systems. She explained the differences of the two parallel worlds in the field of special education. There were the university professors with their grandiose ideas and the need to remain published, and then there was the day-to-day world of meeting goals and objectives within the constraints of school budget, school policy, and school doctrines, and of course avoiding due process. Essentially the message was, "The data be damned, the policy, method, and philosophy will not be changed."

It is now thirteen years latter. My son has been included in his home/base school with supports in some schools better than others. I have found the sharing of research as a parent with my son's teachers is more readily accepted and noted, especially as I bring it to them within the arena of the IEP.

My frustration, though, is that it is I, the parent/advocate that brings this information forward to them, and not the other way around. How I wish that the teachers that I have worked with as both parent and peer had my professor, who happened to also be a medical doctor. When asked how many had read on their own (not as part of an obligatory assignment) a recently published journal article in their field of focus, not a one (well, save for me) raised their hand. He then questioned and castigated the class for their lack of being professionally current in their field. How dare we, he challenged,

Research needs to be accessed and embraced across the divide of special education and general education, as well. ...To have research utilized to effect change towards new processes, methods and applications within the entirety of educational institutions, the audience needs to be more than just the academicians, the special education teacher candidates, and advocates looking for validation of their "outland-ish" requests.

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My personal musings on research & data based advocacy

Continued from page 26

demand from society the respect and dignity of being considered professional when no one knew what currently was going on in their field.

He then challenged us to decide who we would want to perform a life saving procedure on them. Would we select the doctor who last read a medical journal when he received his degree 10 years ago, 5 years ago, last year, a month ago; or the doctor who knew the latest procedures and was aware of studies being introduced even as he was scheduling the operation? Using that analogy he then questioned how we could take someone's child and suggest we knew how best to teach if we had no idea of what was effective.

Research needs to be accessed and embraced across the divide of special education and general education as well. We read in the research and hear in the presentations of that research that good teaching is good teaching and that the special education techniques, and studies is just that, good teaching. But that message is not being well distributed outside of the special education forces. To have research utilized to effect change towards new processes, methods and application within the entirety of educational institutions, the audience needs to be more than just the academicians, the special education teacher candidates, and advocates looking for validation of their outlandish requests.

The special education data and conclusions need to somehow be made accessible to masses. By that I mean, not only those in the special education field, but the larger force within the field of general education and, ultimately, the administration (and not just the director of special education). It is so rare that I encounter information that has "crossed over" to the other journals, or is ready for application on Monday by more than the special educator.

When you look over the inservice programs for the teachers that presents research and its application, they are always divided into two categories, and in the school where I work into two separate books. There are the inservice sessions that focus on curriculum, and then there is the special education inservice that is geared for the special education teachers who hope their charges will be able to access and benefit from the curriculum. It is rare that within either of the inservices you will find a mix in the audience.

It is seen also at the conventions. We sing to ourselves. Look at the National TASH conference — proportionally there were very few administrators (outside of the special education departments) and an equally small number of general education teachers. Those who are there usually are there as a result of a "need to know" because someone has let one of those special education students in their school and in their class.

Comments and questions concerning this article may be sent by e-mail to Donna Martin, <dmartin336@aol.com>

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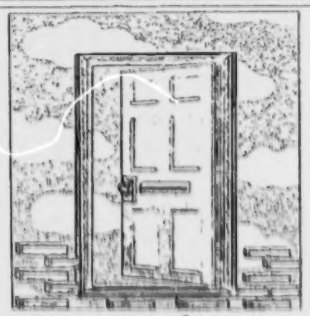

Community for All is Possible: Promoting Home and Community Life at Community Vision, Inc.

BY PAM WALKER

Introduction

Community Vision, a support agency in Portland, Oregon, began in 1989 in response to one person, Phillip (a pseudonym), who wanted to move back home from a nursing home. This experience of supporting Phillip and his family to pursue their vision led, eventually, to the creation of Community Vision, an agency aimed at extending the vision to others with the most severe disabilities.

At the time when Community Vision started, most other agencies in the area offered group homes and other facility-based supports. There was a growing demand for alternatives, as well as growing pressure to close the institution. Thus, Community Vision was created as an alternative to facility-based services that would intentionally focus on providing inclusive community living for those with the most severe disabilities who were still in institutions, nursing homes, and other facilities. The agency currently supports 45 adults in community living, jobs, social relationships, and other community activities. For many people they support, agency staff have assisted in the transition from institution or nursing home to community life. Some people have support 24 hours a day, including a live-in housemate and other staff who provide support during the week days and weekend for jobs, volunteer work, and other community activities; other people receive a few or several hours a day of support.

The lessons the agency has gained from their direct experience of supporting people with severe disabilities in the community, and in their transition back to the community, contribute to the key strengths of the agency. These include a focus on promoting a sense of home, personal control and choice, relationships, and work and meaningful community involvements for people who they support; and an organizational focus on planning and teamwork/collaboration. These combined strengths underpin the agency's efforts to implement a vision of home and community life for all.

A Home and Community Life for All

Based upon their experience supporting people in community life, agency staff have learned that some of the most important aspects of this include having a sense of home; personal control and choice; relationships, particularly those that are nonpaid; and work and/or other meaningful pursuits.

Sense of Home

Community Vision was inspired by Phillip's clarity about wanting to living in a home, rather than a group home. As he put it, "If you move me to a group home I'll bust everything to pieces." Community Vision supports people who rent and own their own homes, who live in houses and apartments, and who live alone and with others. Currently, six people own their own homes. Whether people own or rent their homes, staff place priority on assisting people to establish a sense of home, including stability, security, and personal control.

Robert is one of the people who owns his own home. He is 47 years old, and lived in an institution for 30 years. He was not considered a candidate for community living by many people in the system, due to past challenging behaviors. Community Vision provides 24-hour support in order to enable Robert to live in the community. This includes a housemate who supports him during the evenings and overnight, and two others who support him during the daytimes and weekends. Even with this level of support, the cost for his services is only about $5,000 per month, compared to about $20,000 a month in an institution.
After leaving the institution, he first lived in an apartment, then rented a house. Finally, in 1997, with the support of Community Vision, he bought his own home. Staff helped him in an extensive search for a home he could afford in a neighborhood that he liked. It is a quiet residential street with small houses on the outskirts of the city. He lives there with his dog, Max. He has gotten to know some of his neighbors, who assisted in laying the sod for his front lawn and in putting up a fence for Max.

Personal Control and Choice

Staff at Community Vision believe that personal control and choice are central to a quality life in the community, and that they are particularly important for people labeled with the most severe disabilities and the most challenging behaviors. This includes control and choice across all aspects of their lives, including where and with whom they live, who provides support, relationships, work and pursuit of other interests, and so forth. They recognize that the people they support, many of whom have lived in institutions and other facilities for many years, have had very little control and choice in their lives and that exercising control and choice is a process, not a one-time event.

Relationships

Staff at Community Vision believe that relationships are an essential aspect of community life. They believe that "support" is not just about activities, but that it is equally about presence, relationships, and interconnections. Thus, a major focus for staff is on the development of positive relationships with those they support. In addition, they feel that it is also a critical for people to have nonpaid, community relationships. Staff support this in multiple ways, such as assisting people to develop and/or maintain relationships with family members and co-workers, and to get to know neighbors and other community members through regular participation in neighborhood and community life.

Overall, staff at the agency feel that relationships that people have with staff and with

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others in the community have been critical to positive community experiences. As the director observed, "Most of the time, when the best things are happening for people, it's due to relationships." They feel that it is people's relationships that have helped them through crises. Staff regularly use input from other staff on their team and the agency as a whole in order to generate ideas to promote increased community connections for people they support; when they have had particular difficulty helping someone make community connections, they have used help from outside consultants to assist in thinking and strategizing about this.

Work and Other Meaningful Community Involvements

Community Vision provides support for employment and other daytime pursuits to 34 people (20 of these people also receive supported living services from the agency). A strength of the agency is this focus on a wide variety of work options, including self-employment, as well as other meaningful engagements. Staff at the agency acknowledge limitations in helping to create meaningful daytimes for all of the people they support—primarily, difficulties for a small number of people in figuring out what kinds of work and other engagement are most preferred, and what kind of support works best. However, they have a strong commitment to spending ongoing time and effort to explore different options and strategies.

While this section has addressed some of the components of home and community life that are emphasized at Community Vision, the following section describes some of the ways that the agency approaches these.

Organizing to Support Home and Community Life for All

Two of the central ways that Community Vision is able to support people and families with complex needs is through extensive planning and collaboration. Each is discussed briefly below.

Planning with People

Planning is a central component of support, and over the years staff at Community Vision have gained significant experience and knowledge about planning in ways that facilitate transition to the community for those who have spent many years in institutions and may have been cut off from family and other community connections and experiences. For all those who are supported by Community Vision, this typically begins with 3 months or more of planning. The planning involves initial extensive communication and interaction with the person, family, and/or others who know the person well; this beginning work of establishing positive, trusting relationships lays the foundation that will help them share concerns and resolve disagreements in their ongoing work together. During the planning stages, there may be mixed feelings among those who participate in the process. For instance, in planning with Phillip and his family, the director of Community Vision emphasized, "It was important to acknowledge feelings of both elation and panic."

Overall, as the agency plans with people, some of the key aspects to this include:

◆ Focus is not on disability labels. Rather, they emphasize getting to know people and focusing on their strengths, capabilities, and interests.

◆ They realize that the agency is not for everyone. Sometimes during the course of planning it becomes evident that there is not a good match between what the person wants and what the agency can offer.

◆ A third aspect of planning is that plans are not set in stone; rather, they form the basis for a starting point in the community, from which initial plans may be changed or altered depending on the individual's evolving needs and desires.

◆ Finally, in initial and ongoing planning, realistic constraints on resources are taken into account. At the same time, agency staff are creative in raising money or finding community resources.

Teamwork and Collaboration

Staff at Community Vision see collaboration (e.g., with people with disabilities, families, community members, consultants) as key to their success, particularly in supporting those people who present the most challenges to them. Overall, as previously noted, the ways in which agency staff collaborate with one another, and with those beyond the agency, are key to supporting people with severe disabilities. Within the agency, efforts are made to recruit housemates and other support staff who are willing to work as a team. As one staff member emphasized, "In working on a team, and supporting people, flexibility is one of the most important things.". Staff teams are particularly useful in helping them get beyond the day-to-day issues. For effective teamwork, it is also important that staff feel like they are an integral, valued part of the team.

One aspect of this is the efforts that are made by Community Vision to pass along the vision and enthusiasm about implementation of this vision to all staff. In addition, it is important that the agency attempts to provide reasonable pay and benefits, and to support the staff in other ways. For instance, at one time, at the request of people who are housemates, the agency convened a group for them to share ideas and give support one another. In general, staff seem to feel supported, and this is reflected in the significant number of long-term staff at Community Vision.

In relation to the people whom they support, collaboration is seen not as an alternative to personal choice and control, but as a context within which individuals can best be supported to increase their personal choice and control, without feeling as though this is taking place in isolation. And, in terms of collaboration with families, the agency has significant success in working with families within complex and sometimes very challenging situations. This success is, in part, based on their understanding of the past experiences of families, which have sometimes been very negative. As one staff person commented, "We need to understand they may have had a long history of struggle, so it can take a long time to build trust." Despite the challenges, agency staff have a commitment to stand with families, over the long haul, through both the frustrations and challenges as well as satisfactions and successes of collaboration.

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Finally, as described above, the agency collaborates with a variety of consultants at a local, statewide, and national level on issues ranging from the needs of a particular individual to those related to the agency as a whole. In addition, over the years, the agency has cultivated positive, collaborative relationships with county and state developmental disability representatives, as well as with members of other community groups and organizations. All of these various types of collaborative relationships have benefited the agency and individuals supported by the agency in a multitude of ways.

Challenges

In supporting people with severe disabilities in individualized ways in the community, there are a number of challenges and struggles facing Community Vision that are common to other agencies that are engaged in similar efforts. This section focuses on two key issues: creating a sense of home for people who require 24-hour support and maintaining staff and organizational energy in ongoing work to promote individual inclusion and systems change.

Creating a sense of home for people who need 24-hour support. It has been challenging for many agencies to figure out how to provide 24-hour support to those who need it in a way that promotes a sense of home, rather than a facility-like atmosphere of shift staffing and other routinized schedules and arrangements. In order to do this, many agencies, including Community Vision, have used live-in housemates, who typically provide support in the evening and overnight, while other agency staff provide support during the day. While there are generally many positive aspects to such arrangements, there are also certain challenges associated with them. One is that the housemates are typically not agency staff, and thus it may be more difficult for them to feel connected to and supported by the agency as a whole. It is positive that, as previously mentioned, Community Vision has been responsive to housemates' request for informal group time together. In addition, the agency makes significant efforts to accommodate housemates when they need time off for a family crisis or other reason.

Second is the degree to which housemates themselves have a sense of home and community connections. This will be different in each situation, depending on the personalities and interaction styles of the housemate and the person with disabilities, but it can have a significant impact on the ways in which staff then assist the person to establish a sense of home and community. In order to address issues related to this, the agency has used lessons from past experiences with housemates to better recruit others. For instance, they found that housemates who have some active interests and social networks work out better than those who are more isolated and inactive. Maintaining staff and organizational energy for ongoing work to promote individual inclusion and systems change. On an individual level, sometimes, after a lot of time and effort on the part of Community Vision, families, and others, it still seems as though the agency is struggling to find the best ways to positively support a person. In these situations, it is helpful for them to get the perspectives of others outside the agency, who both offer new ideas and can sometimes recognize positive changes that are not evident to agency staff who have been so closely involved in the situation.

In addition, based on their experience over the years, even when things are going well for a person, staff at Community Vision are aware of the vulnerability of individuals to a change in circumstances that can have a significant impact on their lives. For example, they recognize that staff can be key to people's connections with others, and when those staff people leave, some of the connections may fall apart. In order to address this, they work to have a team of staff who know people well, rather than just one or a few people. And, overall, it is a testament to the agency's commitment to their mission that they have been willing to enter into some complex situations that others have not been willing or able to address.

On the systems level, staff at Community Vision have a number of concerns. They are troubled by the poverty of people they support and of the staff who provide direct support to them. They also have concerns about both the amount of bureaucratic paperwork, as well as the ways it detracts from devoting time and energy to the issues that are most important to people's quality of life. Finally, they express frustration that after so much experience within Oregon and nationwide illustrating that all people can be supported in the community, there is still so much time and energy needed to confront the system's bias toward facility-based, congregate services.

Conclusion

Across the country, increasing numbers of agencies are supporting some people with severe disabilities in individualized, creative ways. At the same time, many of these agencies also still use some forms of congregate, facility-based supports, and it is still somewhat unusual to find agencies that are providing person-centered supports on a routine basis for people with the most severe disabilities.

Inspired by the persistence of Phillip and his family, staff at Community Vision have a passionate commitment to carry this vision forward, making community living possible for all. Without their commitment to this vision, many if not all of those who are supported by the agency would be in group homes, nursing homes, or other facilities. Phillip's life in the institution and then back home, and his death in his home a few years later, serve as a reminder that this vision can and does apply to all people, and as a reminder of the urgency to implement this vision now.

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TASH NEWSLETTER

Priscilla Newton, *Editor*

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It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

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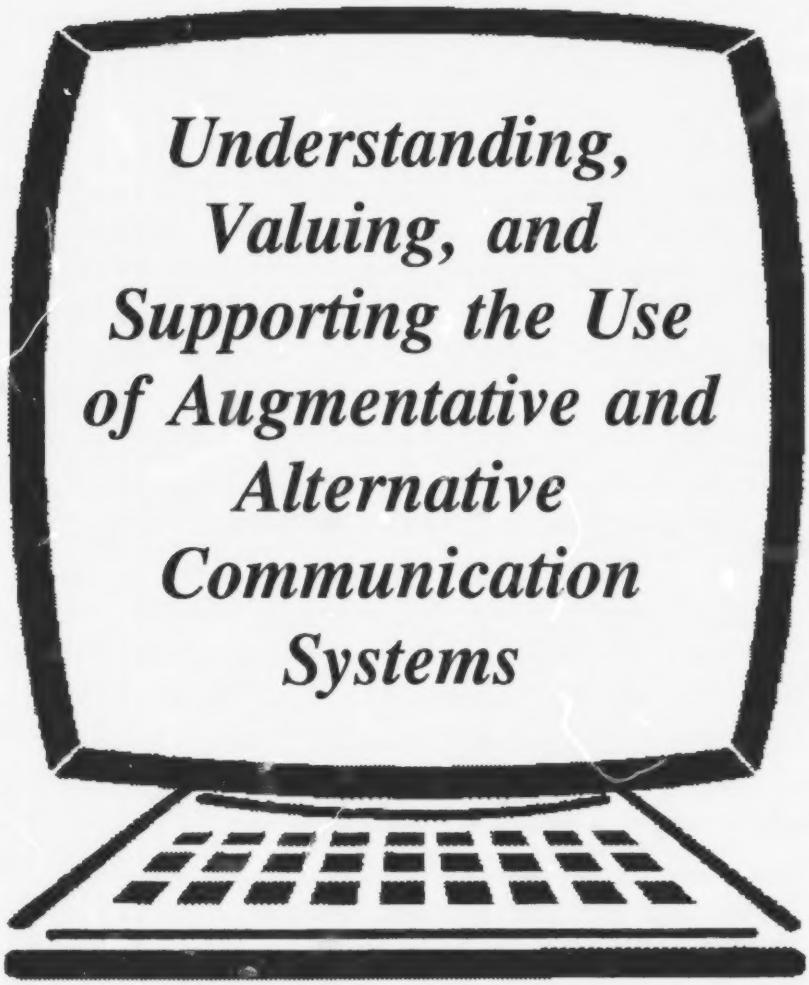
TASH CONNECTIONS

Equity, Quality and Social Justice for People with Disabilities

Inside This Issue

- Communication and Learning: Creating Systems of Support for Students with Significant Disabilities
- Assistive Technology Should Empower People with Disabilities
- Seek Out Opportunities Where Communication Can Happen

2002 Conference Registration Form enclosed! Register before August 15th and save!



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TASH's focus is on those people with disabilities who:

- Are most at risk for being excluded from the mainstream of society
- Are perceived by traditional service systems as being most challenging;
- Are most likely to have their rights abridged;
- Are most likely to be at risk for living, working, playing, and/or learning in segregated environments;
- Are least likely to have the tools and opportunities necessary to advocate on their own behalf;
- Historically have been labeled as having severe disabilities; and,
- Are most likely to need on-going, individualized supports in order to participate in inclusive communities and enjoy a quality of life similar to that available to all citizens.

TASH accomplishes this through:

- Creating opportunities for collaboration among families, self-advocates, professionals, policymakers and other advocates;
- Advocating for equity, opportunities, social justice, and rights;
- Disseminating knowledge and information;
- Supporting excellence in research that translates to excellence in practice;
- Promoting individualized, quality supports;
- Working toward the elimination of institutions, other congregate living settings, segregated schools/classrooms, sheltered work environments, and other segregated services and toward replacing these with quality, individualized, inclusive supports;
- Supporting legislation, litigation and public policy consistent with **TASH**'s mission; and,
- Promoting communities in which no one is segregated and everyone belongs.

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From the Executive Director
BY NANCY WEISS

STOP! There's a Baby in that Bath Water: Embracing the Critical Value of Communication and Facilitated Communication

Earlier this month, TASH organized a historic meeting in Boston that brought together people with autism and national leaders of the disability rights movement. Most of the people with autism who participated in the meeting communicate through Facilitated Communication (FC).Facilitated Communication is an alternative communication method that involves a trained facilitator providing physical support to a person with a disability to allow people who otherwise have limited verbal or written communication skills to communicate through typing.[1] The meeting was made possible through the generous support of the NLM Family Foundation. The overriding goals of TASH's work with the Foundation are:

- to increase the public's and the disability community's understanding of the abilities and potential contributions of individuals with autism and communication differences;

- to explore the barriers that have stood in the way of people with autism becoming full participants in the disability rights movement; and

- to increase opportunities for individuals with autism to have impact on disability-related public policy.

For a person like me who has had only occasional opportunities to observe people using Facilitated Communication, the experience of being in a room with seven FC users and their facilitators, all actively participating in a full-day's meeting on public policy issues, was nothing short of exhilarating.

The validity of Facilitated Communication has been questioned over the years. In speaking to people about this meeting I was shocked at how many people said something to the effect of, "FC? I thought research had proven that all that stuff was a hoax!?". It is true that FC will not work for everyone and that it's a method that requires training, skill, and care to assure the authenticity of the communication. It *is* true that some studies have shown that communications that appeared to be initiated by the person with a disability were in fact generated by the facilitator. In some cases facilitators, without knowledge or intent, have been shown to have influenced the communications of the people for whom they were providing support.

However, numerous studies have demonstrated clearly that the authorship of communications produced through FC are those of the person with the disability (see suggested readings, p. 5). In addition, many FC users all over the country and the world have been able to fade their need for the physical support of a facilitator and now type independently. One can't watch a person typing completely independent of support, or with only a light touch on the back of the shoulder, or a pinch of sleeve fabric held in the facilitator's hand and still imagine that the communications produced could be anything but authentic. *We'd do well to take care not to throw the baby out with the bath water.*

After the meeting in Boston, I told many of the skeptical people I had spoken with prior to the meeting that there was no way they could have been present at the meeting with FC users and come away anything but convinced of the validity of the method. I like to remember what Anne Donnellan has said about the existence of FC. She says, "You can fish all day in a pond and not catch anything, but that doesn't prove that there are no fish in the pond. If, however, you catch just one fish, you know beyond a shadow of a doubt that there was at least one fish in there." It can't be denied that the FC hook has caught some fish - and big fish at that. Imagine the impact that going from being unable to communicate needs, wants, and ideas, to being able to communicate complex thoughts has on a person's life. Though we can assume that this method, like every other alternative communication method is not going to work for everyone in all situations, we know with certainty it is a real phenomenon and that FC not only works for, but creates breathtaking life change for many individuals previously thought to have significant cognitive disabilities.

How is it then, that even leaders within our own disability community recalled the negative messages about FC but failed to pick up on the good news - that thousands of people who had not had an effective way to communicate and who, in many cases were assumed to have severe or profound cognitive disabilities, are now communicating successfully using FC? There are dozens of stories of people who were unable to communicate with words and as a result spent years in institutions or segregated classrooms for children with autism or severe mental retardation who, as a result of being able to use FC, are now living full lives, learning with their peers, going to regular colleges, working in real jobs, and participating as valued members of their communities. What has kept the good news portion of the message from getting through to people?

It can't be that only a part of the story has reached the people I spoke with who expressed doubt about the validity of FC. All are parents or professionals active in disability rights work. There are now numerous research studies published in multiple journals, books, personal accounts, videos and web sites devoted to studying and understanding FC. I sense that there is something so unnerving about this knowledge that it allows even devoted advocates to reject the possibility of its validity.

If we accept that FC works, and unlocks the world for even *some* people with severe disabilities, then we have to accept that we've made some tragic errors of judgement.

Though many new lessons have been learned in recent years, what is not news is that the key to a quality life is access to a communication system that can be used effectively by the individual.

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Embracing the Critical Value of Communication and Facilitated Communication

Continued from page 3

If even only *some* people have been locked away on back wards, or sentenced to a life of wasting time in segregated schools and day programs, only to have us later learn that they are thinking, feeling, people, capable of complex thought and communication, what does this mean about the ideologies to which we have clung? If we have tried to manage only *some* people's primitive, behaviorally-based efforts at communication through restrictive and inhumane means - when given a communication method that works for them they could have told us all along what they wanted and needed - what must we acknowledge about ourselves? Could we as a field of parents, professionals, and advocates be so convinced that what we thought we knew about people with severe disabilities is true, that we need to reject out-of-hand the possibility of a view that challenges the very foundations of our belief systems?

I sometimes begin a workshop on disability issues by asking participants to write down the five or six things they most value. I ask them to think about what motivates them, what in their life is most precious, the stuff they could not live without. Most people write down things like family, love, spirituality and health. Never do I remember anyone writing, "being able to say what I want or don't want" or "the ability to assert myself and determine my own future." In the course of communicating those things nearest and dearest to them, no one has thought to mention the ability to convey and receive information, feelings, choices, and ideas as something they treasure. We tend not to acknowledge the significance of those things we take for granted.

However, ask people who have spent a big chunk of life being unable to express themselves what it is that *they* value most and the ability to communicate tops their lists. In his article on p. 25 of this issue of TASH *Connections*, Pascal Cravedi discusses Troy Daniels' journey toward finding a method of communication that works for him. In discussing what access to communication has meant to him, Troy says: "Now ... I can talk about anything I can type. Now people know that I am smart and that I can think like they do. They are surprised. I am not surprised; I always knew I could think good." And, in the same article, Sarah, an FC user says, "I don't want to be stuck in myself any more. Instead of being just me and no one else, now I can bring others into me ... Asking for the things I want gives me freedom." Janice Staehely is a young woman who, because her speech is difficult to understand, has used a number of communication devices over the years. She knows well the impact of being unable to communicate with ease. She says, "I felt locked inside myself without any clear way of communicating. I had become so used to not being able to say something in depth ... that I started to believe that I was a person who didn't have much to tell people. I fooled myself into thinking that I didn't have anything to say."[ii]

Chammi Rajapatirana, another FC user said, "When you judge me by my muteness and deny me the power of my intellect, we all lose. Ignorance and the lack of assistive technology held us autistic people hostage in the past. How many people lived alone and abandoned, how many lives lost. Hear me now. Ignorance and prejudice still hold too many of us in that silent abyss."[iii]

Over the last number of years we have had to unlearn so much of what we thought we knew about people labeled with autism and/or cognitive disabilities. As more and more people have had access to effective ways to communicate, person after person has taught us new answers to questions we thought we had long ago resolved. We thought we knew that people with autism, for example, were inflexible, uncommunicative, incapable of complex thought, and prone to difficult behaviors. We now know that people who have been labeled as having autism have much to teach us about the critical role communication plays in people's lives.

The liabilities that result from having limited assumptions and reduced expectations of people with autism and other disabilities are great - for people with disabilities themselves, for their family members, and for society at large. Schools, neighborhoods and whole societies grow stronger and prosper; not, as some might imagine, despite the inclusion of individuals with all kinds of backgrounds, abilities and interests, but instead, as a direct result of their diversity. As a society, we lose immeasurably when we do not give each individual an opportunity to communicate, participate, effect social change, and become a valued member of his/her community.

Though many new lessons have been learned in recent years, what is not news is that the key to a quality life is access to a communication system that can be used effectively by the individual. We cannot let our own discomfort and prejudices deny even one more person the right to assert him/herself or to lay claim to a life determined by his/her own interests, goals, and values. Every one of us has a right to a meaningful life in the real world. All individuals deserve the right to a communication system that allows them to stake out a life of their own design and seek the dream of their own making.

<u>References</u>

[i] Facilitated communication is an alternative means of expression for people who cannot speak, or whose speech is highly limited. The method has been used successfully by individuals with severe disabilities, including persons with labels of mental retardation, autism, and other developmental disabilities. The method entails a facilitator providing physical support to allow an individual to type or use a letter board. This support can, in many cases, be faded over time with many FC users becoming independent in their typing and communication. For more information, see the Facilitated Communication Institute's web site: http://soeweb.syr.edu/thefci

[ii] Staehely, J. (2000). The communication dance. Speaking up and speaking out. Baltimore: Paul Brookes Publishing Co. p. 4 & 9.

[iii] Rajapatirana, (1998) C. On being mute. Facilitated communication digest. 7 (1), 6.

Selected Readings Related to Facilitated Communication

[NOTE: Following is an excerpted list of resources on facilitated communication. A more complete listing can be found on TASH's web site at http://www.tash.org/communication/fcreadings.htm]

Biklen, D. (1993). Communication unbound. New York: Teachers College Press. This book includes Biklen's first article on facilitated communication, originally published in the Harvard Educational Review (1990), as well as information about the method and a discussion of how findings from facilitation challenge prevailing understandings of autism and related developmental disabilities.

Blackman, L. (1999) Lucy's story: Autism and other adventures. Brisbane: Book in Hand. Lucy Blackman was at one time thought to have significant intellectual disabilities. She learned to communicate using facilitated communication and now is able to type without physical support and has earned a bachelor's degree in arts and letters from Deakin University in Australia.

Broderick, A. & Kasa-Hendrickson, C. (2001). "Say just one word at first": The emergence of reliable speech in a student labeled with autism. The Journal of the Association for People with Severe Handicaps, 26, 13-24. "As a nonverbal child, Jamie was provided with a text based system of communication presuming that he could and would become literate in reading and writing." p. 23.

Cardinal, D., Hanson, D., & Wakeham, J. (1996). An investigation of authorship in facilitated communication. Mental Retardation 34, 231-242.. The largest scale validation study to date. Forty-three individuals were asked to type words that they had seen but their facilitators had not seen. Seventy-four percent of the participants demonstrated that facilitation aided them in conveying words their facilitators had no way of knowing.

Crossley, R. (1997) Speechless. New York: Dutton. This book, written by the Australian educator widely recognized as one of the first to use facilitated communication, and certainly the first to prove the method's effectiveness through validation tests, includes a series of case studies of her work.

Donnellan, A.M. & Leary, M.. R. (1995). Movement differences and diversity in autism/mental retardation. Madison, WI: DRI Press. The authors explore the idea that conceptions of mental retardation have failed to acknowledge the importance of movement disturbance in relation to communication.

Eastham, M. (1992). Silent words. Ottawa: Oliver Pate. A mother's account of how her son learned to communicate with facilitation and to become an independent typist.

Facilitated Communication Institute (2000). Facilitated Communication Training Standards. Syracuse, NY: Author. Available on-line at: http://soeweb.syr.edu/thefci This document explains the fundamental principles of facilitated communication, best practices, methods of training, and competency levels. Appendices include a bibliography as well as a supervision check-list and skill building elements.

Grandin, T. & Scariano, M.N. (1986). Emergence labeled autistic. Novato, CA: Arena Press. A classic autobiography by Temple Grandin about her life with autism. This is not a book about facilitation, but it is nevertheless important to understanding facilitation, for many of her experiences parallel those reported by people who now use facilitation.

Jacobson, J. W., Mulick, J.A., and Schwartz A.A. (1995). A history of facilitated communication: Science, pseudoscience, and antiscience, American Psychologist, 50 (9), 750-765. Starting with a biting attack of facilitated com-munication, the authors suggest that this method's acceptance is related to "anti-science" views that they say have led to deinstitutionaliza-tion and inclusion which the authors also attack.

Kliewer, C. & Biklen, D. (2001) "School's not really a place for reading": An analysis of the literate lives of people with severe disabilities. The Journal of the Association for Persons with Severe Handicaps, 26 (1), 1-12. Suggests "that people construed as having severe intellectual disabilities demonstrate a symbolic and literate presence when supported by those who believe in their capacities and with whom they share an intimate relationship." p. 11.

Marcus, E. and Shevin, M. (1997) Sorting it out under fire: Our journey. In D. Biklen and D. Cardinal (Eds.) Contested words, contested science: Unraveling the facilitated communication controversy. New York: Teachers College Press. In this article, Marcus who has autism replicates the Wheeler study cited below. Then with modest modifications (e.g. numerous practice sessions, extended time to answer, etc.) demonstrates that he is the author of the words he types with facilitation.

Muckopadhyay, T.R. (2000). Beyond the silence: My life, the world and autism. London: National Autistic Society. An autobiographical account by a boy who learned to communicate with physical support and who now types independently and can speak.

Reed, D. (1996). Paid for the Privilege. Madison, WI: DRI Press. This is a facilitator's humorous and poignant account of learning about disability from people who had grown up without speech and who were believed to have mental retardation.

Rubin, S., Biklen, D., Kasa-Hendrickson, C., Kluth, P., Cardinal, D.N., & Broderick, A., (2001). Independence, participation, and the meaning of intellectual ability. Disability and Society, 16 (3), 415-429. "I was thought to be retarded (but) all this changed ... once I could type without support... My very existence challenged beliefs about mental retardation. My presentations (at conferences) were acts of advocacy.... When people see me they are forced to admit that their assumptions about mental retardation were wrong."

Sheehan, C. & Matuozzi, R. (1996) Validation of facilitated communication. Mental Retardation, 34 (2), 94-107. "Three individuals with diagnoses of autism and mental retardation participated in a study to determine whether they could disclose information previously unknown to their facilitators. Results showed valid facilitated communication from each participant." (p. 94)

Spitz, H.H. (1997). Nonconscious movements: From mystical messages to facilitated communication. Mahwah, NJ: Lawrence Erlbaum Associates. The author argues that facilitated communication is a hoax, much like the Ouija board, mind reading, and other magical tricks.

Taylor, S. (1994). Editor's introduction to the exchange of opinion on the risks and benefits of facilitated communication. Mental Retardation, 32 (4), 299-300. Introduces article by Levine, Shane, and Wharton. Commentaries — most of them are critical of the Levine et al. framework and conclusion— are offered by Ferguson & Horner, Goode, Halle, and Hitzing, with a rejoinder by Levine et al.

Williams, D. (1994). Invited commentary: In the Real World. Journal of the Association for Persons with Severe Handicaps, 19, 196-199. Best selling author, Donna Williams, gives a brilliant critique of arguments on both sides of the facilitation debate; she offers her own explanations for why the method may work and also why some people may easily be influenced in their communication. This issue of JASH includes articles by Green & Shane and by Biklen & Duchan, as well as other commentaries on facilitated communication.

TASH: Public Policy in Action

Bringing the Power of New Technologies to Children with Disabilities

TASH has joined with a distinguished group of organizations and corporations to develop proposals to incorporate principles of universal design into the Individuals with Disabilities Education Act. Our interest in this proactive effort is high in that universal design concepts hold great promise for creating educational opportunities that go beyond access, and truly result in active participation and progress in the general curriculum "reachable" for all students, with and without disabilities.

Students who have sensory, cognitive and physical difficulties each have different ways of receiving, processing and expressing information. Universally designed technologies allow access to be built into educational programs right from the start. Universal design use in educational settings requires identifying the needs of the broadest possible range of students and then designing technology and interfaces that can enable children with varying abilities and needs to benefit from those technologies.

"The term 'universal design' means a concept of philosophy for designing and delivering products and services that are usable by people with the widest possible range of functional capabilities, which include products and services that are directly usable (without requiring assistive technologies) and products and services that are made usable with assistive technologies" (from the Assistive Technology Act (ATA) of 1998 P.L. No. 105-394).

The first work group briefing was held May 9, 2002 and was sponsored by the Center for Applied Special Technologies (CAST), WGBH National Center for Accessible Media, the American Association of People with Disabilities, and the Center for Children and Technology and underwritten by Venison.

Board President Donna Gilles and Jamie Ruppmann, Director of Governmental Relations, represented TASH at this meeting. The work group is continuing to meet and finalize amendments to existing IDEA legislation, develop recommendations for personnel preparation and training activities, as well as funding targets. The recommendations will be posted on the TASH website as soon as they are finalized.

Congress and the Administration Completing IDEA Reform

The President's Commission on Excellence in Special Education will complete their draft recommendations prior to their final "consensus" meeting scheduled to be held May 30 and 31 in Washington D.C. The House Subcommittee on Education Reform will consider these recommendations as they put forward IDEA "reform" proposals July first. The Senate Health, Education, Labor and Pensions Committee has scheduled their final hearing on IDEA Accountability for June 6 and have indicated that their "reform" language proposals will be released June 14.

TASH staff have been updating and expanding the Governmental Relations section on the TASH web site. Take time to visit <www.tash.org> and be sure to take advantage of our links to the House and Senate Committee Members working on the IDEA Reauthorization as their proposals are put forward.

For questions, ideas and additional information contact Jamie Ruppmann, (410) 828-8274 x104 or email jruppmann@tash.org

Project Coordinator
Institute for Community Inclusion
University of Massachusetts Boston

The incumbent manages federally funded educational improvement, leadership, and personnel preparation projects at the Institute for Community Inclusion (ICI). Duties include coordinating working groups of faculty and staff; building relationships with public high schools; conducting presentations and training; developing a written model of IHE restructuring; managing master's and doctoral degree student affairs; advising doctoral students; participating on dissertation committees; coordinating program evaluation; grant and program development. Qualifications: Ph.D. in education and/or special education or educational administration/leadership. At least 5 years' full-time professional experience in teaching or a combination of teaching and educational administration. Experience educating students with disabilities in inclusive classrooms. Knowledge of issues in urban education, school reform, inclusive education. Familiarity with educational pre-service training practices. Strong interpersonal, written and oral communication/presentation skills. Ability to travel statewide. Hiring Salary Range: $52,409-$62,892. Normal Starting Salary Range: $52,409-$57,650.

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TASH RESOLUTION ON THE RIGHT TO COMMUNICATE

Statement of Purpose

The right to communicate is both a basic human right and the means by which all other rights are realized. All people communicate. In the name of fully realizing the guarantee of individual rights, we must ensure:

- that all people have a means of communication which allows their fullest participation in the wider world;
- that people can communicate using their chosen method; and
- that their communication is heeded by others.

Where people lack an adequate communication system, they deserve to have others try with them to discover and secure an appropriate system. No person should have this right denied because they have been diagnosed as having a particular disability. Access to effective means of communication is a free speech issue.

Rationale

Access to Communication. All persons with disabilities should be provided therapy and training directed towards permitting them to communicate freely. All people with communication disabilities should be given the full opportunity to use augmentative and alternative communication. "Access" includes a) access to assessment to judge the suitability of the method, b) access to training in the method, c) access to any equipment needed, both in the short term during training and in the longer term for continued use on a daily basis if training is successful, and d) access to training for support people so access to communication can take place across environments.

Education. Instruction in communication is an essential element of the education of people with communication disabilities. People using augmentative or alternative communication must be given any assistance necessary in order to communicate with others at school or in their educational program. Any equipment, training or staffing necessary to enable communication to take place must be supplied, both to that person and to those with whom he or she wishes to interact on a regular basis. The collaborative education team must ensure that all such communication equipment, or comparable equipment, follow the person when transitioning away from the school.

Freedom to Communicate. No person should be able to veto the use of another person's augmentative or alternative communication, and in any instances where such use is forbidden, there should be recourse to the legal and protective systems. People with communication disabilities must be allowed to use the communication system of their own choice in all communication interactions in any setting.

Legal Issues. People using augmentative communication must be permitted to use the system of their own choice in court. Any person using a communication strategy requiring the involvement of another person to receive and relay their communication must be permitted to use the partner of their choice in court. Each state's protection and advocacy system should develop the resources needed to support such full participation in the legal process.

Presumption of Competence in Decision-Making and Advocacy. People are presumed to have an active interest in decisions affecting their lives on a short-term and long-term basis. In planning or decision-making on a person's behalf, that person's participation must be ensured regardless of the formal communication modalities used. This may include the involvement of allies, advocates and communication partners before and after meetings, and may also include the involvement of a "communication ally" during the course of the meeting.

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Communication and Learning:

Creating Systems of Support for Students with Significant Disabilities

BY MICHAEL McSHEEHAN, RAE SONNENMEIER, AND CHERYL M. JORGENSEN

IDEA 1997 requires that students with disabilities have access to the general education curriculum; that they pursue learning goals that are "consistent with those of students without disabilities" to the "maximum extent appropriate;" and that they "make progress" within that curriculum. For students who have traditionally been given labels of mental retardation, autism, deaf-blindness, traumatic brain injury, and multiple disabilities, realization of these goals presents significant challenges.

In many schools, access to the general education curriculum occurs in segregated settings and the standards that students pursue are minimally related to the academic content of that curriculum, focusing primarily on "access" skills. Even when students are enrolled in general education classes, staff may not have access to high quality professional development around evolving best practices, effective team functioning, and leadership skills. This article illustrates how the IDEA intent can be met for student with the most significant disabilities.

Jared's class is working in pairs on writing a collaborative story. Jared and his classmate are deciding on the topic for their story. The paraprofessional coaches the classmate to write out choices of different topics to write about on two pieces of paper (e.g., baseball or computer games, Olympics or visiting grandma.) Then, the classmate holds up each piece of paper, reading it aloud to Jared. Jared looks to the left and the classmate says "You want to write about baseball in our story. Great. I love baseball." The choice making continues as Jared and his partner collaborate to write the story. The classmate writes words or phrases related to baseball (e.g., hitting the ball, watching the game, hitting a grounder, eating a hot dog) in two quadrants of a white board and presents them to Jared to identify his preference. The classmate builds the story sentence by sentence, adding his own elaborations and looking to Jared frequently for direction and affirmation. The speech language therapist and occupational therapist have collaborated to ensure that Jared is seated so that he can easily view the choices and that the choices are phrased appropriately. They are exploring how to present choices to Jared that will facilitate his participation in classroom activities.

Members of the team look on in awe as the classmate accepts Jared's choices and uses them in writing the story. Jared has labels of "mental retardation" and cortical blindness, and seemingly has no effective means of communication. The team has been working with Jared outside of the classroom on cause-effect activities to improve physical access to a communication system. No one thought he would be able to participate in a classroom activity since they have been so unsure of what he "knows."

Exceptions to the rule. Unexpected skills. Misdiagnosed disabilities. These kinds of statements about students with significant disabilities pervade our professional literature and our workplace conversations. We have grown heartbreakingly comfortable with the notion that educational success for students with disabilities is more related to the characteristics of the disability itself than to the way that supports are provided to the student. We write reports, develop IEPs, deliver therapies, and teach classroom lessons, pointing to the deficits in "them" and naming the goals "they" must reach to demonstrate progress. We include a description of our procedures and the "conditions under which" the student must perform. We list the accommodations and modifications that we will provide. But during instruction and the ongoing provision of supports, how often do we document the actual accuracy and consistency - the quality - of "our" supports? How often do we evaluate a student's demonstration of learning in the context of our ability to provide the necessary instructional and communication technologies? How many of us even know what those supports should be?

We have grown heartbreakingly comfortable with the notion that educational success for students with disabilities is more related to the characteristics of the disability itself than to the way that supports are provided to the student.

Communication is the primary method of demonstrating learning in a classroom. Without a thorough examination of the supports provided to students in this context, we cannot clearly and confidently

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Communication and Learning: Creating Systems of Support for Students with Significant Disabilities

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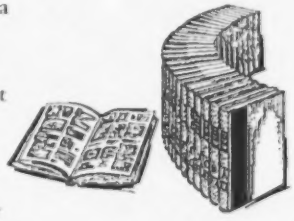
speak to their abilities. Without increasing our knowledge and skills in supporting various means of communication, we will not see increases in the full participation and learning by students in the classroom. Our awareness of the relationship among communication, curriculum, and quality supports is becoming increasingly clear. However, this awareness is not present among practitioners in most schools.

So what beliefs, knowledge, and skills must a student's team have in order to provide effective supports for communication, access to the general education curriculum, and to assure that students will learn?

(1) Hold high expectations and monitor decision-making regarding student performance using the least dangerous assumption. Donnellan's principle of the least dangerous assumption (1984) is a best practice in educational programs for students with significant disabilities. When students do not have a way to demonstrate their knowledge because of significant communication difficulties, Donnellan asserts that teams ought to assume students' competence, because to assume they are NOT competent would have dangerous consequences for that student, should the assumption ever be proven wrong.

Knowing how important contextually-based learning is to students with significant disabilities - how could [a student] possibly demonstrate literacy abilities unless [he/she] were included in literacy-learning activities and provided with a means to communicate about the topics and ideas that comprise the curriculum?

There are a growing number of examples from the literature in augmentative communication, literacy, and special education documenting students' demonstration of "unexpected literacy" skills when they are held to high expectations, included in general education classrooms, and provided with adequate communication and instructional supports (Erickson, et al., 1997; Koppenhaver, et al., 2001; Ryndak, Morrison & Sommerstein, 1999). Prior to Jared's inclusion in daily literacy activities he was not demonstrating reading or comprehension abilities. He was stuck in a Catch-22 of low expectations, pre-requisite skills, and lack of access to communication, curriculum, and typical classmates.



(2) There is a growing body of literature that supports improved educational outcomes for students with significant disabilities when they are included in general education classrooms with classmates without disabilities. McGregor and Vogelsberg (1998) identified improved learning in the following skill areas when students were included in general education classrooms and had contact with typical classmates: academic learning, communication, social interactions and social competence, and friendships. The importance of providing supports for communication system use within natural, everyday situations such as the general education classroom is now well-accepted by practitioners and researchers in augmentative communication as a means of facilitating meaningful communication and participation in daily life activities (Beukelman & Mirenda, 1998; Calculator, 1988; Goossens', 1989; Montgomery, 1987; Romski & Sevcik, 1998).

The speech language therapist on Jared's team met regularly with the classroom teaching team to plan for the ways Jared would communicate during curricular activities. Attention was paid not only to the means of communication, but to the strategies that classmates and adults could use to support Jared to be an active participant in the learning activities. Strategies included the specific ways to offer Jared a choice, ways to "read" his body language, and reminders to talk to Jared like they would talk with other classmates. The speech language therapist regularly provided support in the classroom to coach classmates and members of the teaching team as needed.

(3) An outdated practice from the early 1980s that is sometimes still observed today, is for practitioners to withhold augmentative communication interventions unless students demonstrate at least sensorimotor stage V cognitive skills (Shane & Bashir, 1980). This practice was based on assumptions derived from research on typical child development (see Bates, et al., 1977 for an example). Kangas and Lloyd (1988) questioned the validity of these assumptions and persuaded the field that there was no reason to require the achievement of some cognitive prerequisite prior to augmentative communication intervention. "Everyone can communicate; Everyone does communicate" (Beukelman & Mirenda, 1998, p. 158).

Knowing how important contextually-based learning is to students with significant disabilities - how could Jared possibly demonstrate literacy abilities unless he were included in literacy-learning activities and provided with a means to communicate about the topics and ideas that comprise the curriculum?

(4) Evaluation and assessment must be done in typical contexts and be continually informed by student performance within those everyday learning activities and environments. Snapshot evaluations that only capture an incident of failure often reflect poor supports rather than lack of

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knowledge or skill by the student. "Assessment is not a one-time process" is a best practice promoted within the special education, augmentative communication, diagnostic teaching, and authentic assessment literature (Beukelman & Mirenda, 1998; Glennen & DeCoste, 1996; Snell, 1993). Interventions and supports should undergo continual revisions and refinements and provide a process to support the team in critically analyzing performance data and making appropriate adjustments to instruction, technology, and supports over time. Jared's teacher used naturally occurring opportunities to assess his knowledge, such as "Daily Oral Language" exercises, weekly journal entries, weekly spelling tests, and other writing assignments.

(5) Students often display unexpected abilities after they have been provided appropriate educational and communication supports. Educational teams can postpone "assessment of knowledge" until students have an accurate and reliable means of communication (Goosens', 1989) and until the supports provided to them are of high quality.

Some members of Jared's team were initially concerned that they did not know his true abilities and thought that he needed to demonstrate certain prerequisite skills, such as cause-effect, prior to introducing any supports for communication. Once the team began supporting Jared to communicate within various curricular activities about the same things that his classmates were talking about, Jared had more opportunities to "practice" his communication skills in the classroom. His classmates talked with him more often as did the adults, and this allowed him to share his interests. As the team members and classmates built their skills in supporting Jared, he was able to show more of what he "knew."

(6) Romski and Sevcik (1998) noted the importance of examining both the accuracy and the consistency of student performance over time, recognizing that both of these measures are necessary in determining confidence in a student's learning of the communication system and curricular content. Participants in their study showed increased accuracy and consistency over time when supported to use communication systems in classrooms and everyday situations.

Jared's team met every other week to examine Jared's work and to reflect on how accurately and consistently they had provided supports to him according to a plan developed at the beginning of the year.

(7) Many schools support high-quality professional development and collaborative teaming in recognition of the difficulties experienced by practitioners in bridging the research-to-practice gap in both education (Garmston & Wellman, 1999) and augmentative communication (McCarthy, et al., 1998). Schools can apply the accepted standards for the design of high quality professional development for staff, and enhance current practice by providing teams with strategies for linking their professional development plans directly to student learning goals and performance results (Danielson, 1996).

Teams play an important role in supporting a student with significant disabilities (Giangreco, Cloninger, & Iverson, 2000). Schools can apply principles of collaborative team planning (Thousand & Villa, 1992), transdisciplinary and integrated service delivery by related service providers, and enhance current practice about how to support student learning within the context of the general education curriculum (Rainforth, York, & Macdonald, 1992).

In their biweekly meetings, Jared's team members evaluated their effective and efficient use of meeting time, and their success collaborating. Additionally, they monitored a list of knowledge, skills, and practices each had prioritized for their overall professional development. As new supports were identified for Jared, they checked to ensure that their professional development activities directly increased their capacity to provide Jared's supports.

The Beyond Access Model

Through our work with school teams, we have combined the aforementioned best practices into a model for planning, evaluation, and professional development related to designing student and team supports that promote the student's learning of general education curriculum content. The "Beyond Access" Model (Figure 1) involves a 4-Phase Recursive Planning Process.

Figure 1. Beyond Access Model for Planning and Evaluating Student and Team Supports that Promotes Learning of General Education Curriculum Content

Phase 1 of the model is a needs assessment of the student, family, and team. Phases 2, 3, and 4 are recursive processes that teams use as

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they plan, implement, evaluate, and refine the supports provided to the student and the team so that its members can perform their roles effectively and efficiently.

"Team" is meant to include all of the individuals who have contact with the student throughout the day, including all teachers, related service providers, paraprofessionals, other students, and the family. The team is not meant to be limited to the professionals who attend the IEP meeting.

The processes described take place within the context of the classroom and school building environments, depicted by the large circle. At the base is a solid foundation of high quality professional development. Team members work on specific instructional and communication strategies, and build their skills needed to effectively support the student's learning.

"We don't know what he knows. How do we get started?"

Phase 1: Needs Assessment. During the needs assessment, team members, the family, and others within the school complete three steps:

a) develop an orientation to the student, family, and school situation, including any questions or concerns;

b) gather specific information about the student, family, and team; and

c) synthesize information gathered from the needs assessment to provide a deeper understanding of the situation, including team functioning and capacity in supporting the student's learning.

These steps occur through discussions with team members, family members, and school administrators; reviews of relevant reports; completion of written questionnaires; observations in school; and interviews with family and team members. The relationship between the student's individualized learning objectives (from the IEP) and the general education standards is discerned. Information is gathered about how the team members work both in the classroom and during team meetings.

A summary proposal describes the variables that will be the focus of the Explore & Describe phase and the kinds of professional development that might be needed by the team.

"What should we be doing with him? How do we get everything prepared that he needs for learning?"

Phase 2: Explore & Describe. With the completion of the preliminary student support plan and professional development proposal, team members enter the second phase of the planning model. This phase consists of exploring specific strategies that will support the student as a learner, enhance the learning environment, and develop meaningful and relevant supports.

During this planning phase, detailed observations are made of how the student communicates, his curricular and instructional needs, and the environmental supports that seem most effective. Attention is paid to the features of an effective augmentative communication system that will promote participation and learning. This exploration of features (see Beukelman & Mirenda, 1998; Glennen & DeCoste, 1997) takes place while the student is participating in the general education classroom and includes consideration of:

a) ways to physically access the communication system (direct or indirect methods of selection);

b) seating and positioning that enhance access;

c) the type of symbol(s) and the messages of instructional activities and conversation;
d) color-coding;

e) size of symbols;

f) number of items on the display and their placement; and

g) output (voice, print)

The "least dangerous assumption" philosophy (Donnellan, 1984) will guide team members as they design students' communication systems so that each student has vocabulary on his system that is related to the academic learning standards, regardless of the label the student has been given or any prior assessment of his I.Q. or "developmental level."

Aspects of the instructional environment are explored and described during this phase as well, including:

a) the content of the classroom curriculum, with attention to whether the student is pursuing the same learning standards as other classmates;

b) possible ways of modifying and enhancing how the teacher organizes instruction over time;

c) potential accommodations and modification of materials; and

d) considerations for accommodations and modifications of the teacher's instructional style and formats (lecture, small group, labs).

Suggestions are considered for ways to align the student's individualized learning objectives (from the IEP) with the general education standards. Strategies for how the team members work together both in the classroom and during team meetings are discussed and explored. And finally, the team will describe how to evaluate student learning (e.g., homework, quizzes, projects, demonstrations) and the criteria that will be used to judge the quality of that work (e.g., rubric, letter grades, numerical grades).

At the conclusion of this phase, the team develops three products: 1) a detailed student

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support plan, that includes specific design features of the student's communication system and recommended accommodations and modifications of learning materials; 2) a plan for the professional development that needs to be offered to individual team members related to the implementation of the student support plan; and 3) a plan for evaluating the team's effectiveness in providing the student supports.

"We have all these ideas of what to do, but how do we know what really makes a difference? How will we keep track of all this stuff?"

Phase 3: Observe & Document. During Phase 3, the student and team support plans are put into place and team members engage in professional development activities. During this phase, the team's focus will be on improving the physical control of the student's body to accurately select specific items from a communication display within academic activities, not on answering the question "what does this student know?"

A checklist is developed to guide and document the ongoing delivery of supports. Team members assemble student work samples, videotapes in instructional situations, and data on the use of the communication system. Data are gathered on the student's accuracy - as defined by communicating and participating with support within classroom activities - and on the student's reliability - as defined by an increase in predictability of performance over time. Finally, evidence is gathered related to team performance in delivering supports to the student based on the supports checklist. Student and team performance evidence is then reviewed in the next phase.

"Now that we have all of this information, how do we make sense of it all? We're not very confident in his performance nor in ours."

Phase 4: Review & Reflect. During this phase of the Beyond Access model, student and team performance data are reviewed. An important topic for team discussion and reflection is how the student's accuracy and reliability vary according to how supports are being provided. The team then engages in structured reflections on these data and determinations are made about the team's "confidence" that the student work is reflective of the student's actual understandings and skills. In this phase, a discussion is also conducted concerning how closely the actual supports provided match the original student support plan.

For example, if an essential component on the student support plan was preprogramming of the communication device with vocabulary related to class discussions in history, yet this was not done, then the confidence that the team has in the student's responses during class will be low. The team might then conclude that "in order to evaluate what this student knows about history, we will have to improve our supports" rather than "the student really didn't learn anything about history during this unit. It doesn't make sense for him to be in the class." This aspect of the model reinforces the notion that student learning outcomes are strongly influenced by the quality of the supports provided by the team.

The products of this phase of the process are a set of recommendations and revisions. Additional areas will need to be explored and described to assess whether they should be integrated into the student or team support plans (recycle through Phase 2). Or it may be that the team develops a new revised student support plan and/or a revised team support plan for delivering those supports, recycling through Phases 3 and 4. This will lead to further collection and analysis of student and team performance data, review and reflection of the performance summaries, and making of further revisions to the support plan and communication system to increase confidence in the student's work and the quality of team performance.

Conclusions

Schools are struggling to implement the promising practices that characterize successful inclusive education and their capacity to develop effective communication and instructional supports is in its infancy. The Beyond Access model presents a way for teams to improve student learning and team functioning. While using the model may at first require outside technical assistance, the recursive nature of the model encourages true capacity building for teams over time, leading to improved access and achievement for students.

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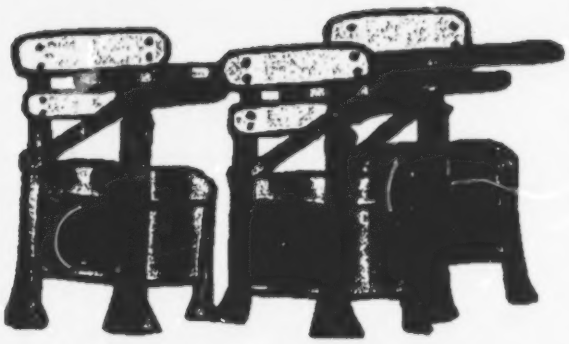

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A Request to Reconsider Facilitated Communication:

Some Ideas, Evidence, and the Presumption of Competence

By Donald N. Cardinal, Ph.D.

Few, if any, educational strategies have shaken the field of severe disabilities as has facilitated communication. Conclusions of studies regarding the efficacy of facilitated communication are greatly discrepant as evidenced by the classic debate in the 1994 edition of JASH. (Biklen & Duchan, 1994; Green & Shane, 1994). More current studies reveal the same general pattern. On one extreme, those who hold science as their sole guide, refute any benefit from facilitated communication, in fact, many have labeled it a hoax. On the other, those who embrace "multiple ways of knowing" have found something in facilitated communication which has challenged their deepest understanding of disability.

Personally, I do not think facilitated communication should be treated as a religion—something one should believe in or not believe in. Rather, facilitated communication should be viewed as a tool, similar to other instructional strategies. This tool can be used poorly or it can be used effectively. Have I witnessed the poor use of FC? Yes, absolutely — and when I do, it hurts me deeply. But the hurt is no greater than the pain I feel when I see the misuse of behavioral strategies across this country or the unbearable disrespect I see continually by those entrusted with the development of people who possess labels. My pain is greatest when I see someone whom I know is "smart" treated as incompetent by those who are paid to be the "teachers."

Those who presume incompetence of those we support, will have, and have had, great difficulty with facilitated communication. How can it be that someone we "know" to possess severe cognitive limitations can be able to communicate effectively? For many, the two are incompatible — like oil and water. However, for those who presume that people *are* competent, the two (having a label and demonstrating intellect) are very compatible, even expected. When we presume incompetence, and little learning occurs, we assume that it is clearly the fault of the learner, not the teacher — "the learner is incompetent, it's not my fault!" For those who presume competence, the responsibility for low learning rates is on the professional. Thus, for them, the difference between low and high demonstrated competence is a product of the effectiveness of strategies and instruction; low learning rates are not attributed to the student's incompetence. The presumption of incompetence should be penalized in our system, while the assumption of competence should be rewarded. Using facilitated communication as a case study, the opposite seems to be true. That is, it has been easier for far too many of us to believe the dogma of presumed incompetence than subscribe to the new paradigm of the presumption of competence.

It is critical for the reader to embrace the notion that there is a difference between *demonstrated* competence and the *presumption* of competence. The construct of presumed competence fully acknowledges the lack of demonstrated competence by some, in specific areas, but the embracer of presumed competence expects the demonstration of competence at any moment. That demonstration may never happen, but it is the expecting of that competent behavior, where it did not previously exist, that differentiates the two groups. For more information about the presumption of competence, see Biklen & Cardinal, 1997.

Dear reader, relax. I have no intention of asking you to presume the competence of all people without some evidence. After all, I was raised in the behavioral system we have created around much of disability study and thus am a part of it. I am primarily a quantitative researcher, I teach statistical research methods, and I still think systematically. However, there is this group of people, their names are Sue, Sharisa, Eugene, Peyton, Lucy, Annie, and many others. Their connection to one another, and to this story, is that they use facilitated communication and they have been able to demonstrate competence despite the fact that their bodies, speech, and actions sometimes appear counter intuitive to what they are typing. For the group of professionals I described above as adhering to a presumptioning of incompetence, they must explain the success of these facilitated communication pioneers as anomalies rather than as evidence for the validity of facilitation. It would seem that at least the two explanations should carry an equal chance of possessing some truth.

Facilitated communication is no simple strategy. It does have some idiosyncrasies which we have not been able to fully explain, and even some characteristics we do not understand. However, our inability to not completely understand this phenomena should not stop us from trying to understand facilitated communication in a deeper, more meaningful way. The lack of ideal understanding of why a technique produces the effect it does or why it is more effective with some people than others, or what are the best conditions under which to use a new instructional technology, is something that has never stopped us before. I am old enough to remember the early days of behavior modification. Such methods were used regularly, without proper training of the users, without an ideal understanding of why it worked — we got better as we went along.

Another example is vocational transition. We, as educators, jumped on this new and wonderful technology. TASH conferences were chock-full of demonstrations of model programs and sessions about how to support individuals to do meaningful work. Then there is the inclusion movement. What we put forth as early ideas of "integration" seem so backward to us now. If you remember these early movements, you will also remember that we did not have an ideal understanding of any of them. In fact, we learned as we went along. Today, what we know as the effective practices of positive behavioral supports, supported employment, and full inclusion, are very different from practices during the early years of each of these movements.

During this time we have learned as much about facilitated communication as we have about the other strategies. We've learned about having the communicator look at the keyboard when typing, fading physical support as soon as possible, and how to promote independent typing, among many other issues. When we are real honest with ourselves, we cringe when we think of the mistakes we made and how naïve we were with each of the strategies mentioned above. But, hopefully more often, and definitely more importantly, we pat ourselves on the back for the many ways we all have helped shape this new world, where people with disabilities receive better services today and are promised a higher quality of life than ever in our history. It is this pioneering spirit that has been the hallmark of TASH — the relentless, deliberate, and fearless search for

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new methods that will increase the quality of life of those on whose behalf TASH advocates.

Then why are we so fearful of facilitated communication? What about it scares us to the degree that we, as a field, must either shy away from it or fight against it as if it were an enemy attacking our very core way of living? A quick examination of the rhetoric against facilitated communication reveals a form of logic that is, in my opinion, dangerous to the population we support and on which all TASH values are based (the length of this document does not permit me to cover this issue in great detail although I would be happy to do so in a future article). In general, critics say facilitated communication is dangerous. They most frequently cite, first, the false accusations of sexual abuse typed by the user of facilitation and, second, manipulation by the facilitator (sometimes called facilitator influence).

Claims of sexual abuse: In comes Botash, 1994, who conducts a thorough medical investigation of sexual abuse allegations through facilitated communication. The author concludes that allegations of sexual abuse through facilitated communication were at least as likely to prove founded in truth based on medical evidence as were allegations from those who reported the claims of sexual abuse through speech. So, this should either end that controversy or other studies should refute those findings, right? Neither has been the case, yet the rumor prevails. "We must protect our children and fathers against this horrible plot" the critics *still* seem to be saying.

Manipulation by the facilitator: Then there is the critique that all messages in facilitated communication are manipulated (benevolently, the critics say this could be done unknowingly) by the facilitators. Yes, there is facilitator influence. Some of the influence may be intentional. Some facilitators have come forward to admit to such despicable actions. However, similar unexplainable aberrant behavior occurs every day with other methods. The brother of one of my best friends was murdered by his attendant who claimed, "I could not stand to see him like this." Yet, we do not wish to end the use of personal attendants. We work to build better understanding and appropriate protections against abuse.

Then there is the unintentional facilitator influence. No one denies this type of influence is an issue with facilitated communication. But the critics seem to be saying that all facilitated communication is a product of facilitator influence. This is clearly not the case. Any reasonable person can read a huge study we did and published in 1996 using 43 individuals and over 4000 trials under highly controlled blind conditions and found that many users of facilitated communication were able to type words using facilitated communication but were not able to type those same words not using facilitated communication (Cardinal, Hanson, & Wakeham). The critics say that the communication was only using single words and thus was not true communication (really, that has been put forth several times). In an international newsletter, one critic stated in explanation of these findings, that there are two forms of communication, one is real communication and the other is the type found in the Cardinal, Hanson, & Wakeham, 1996 study [sic].

Now let's look at the social validation of authentic communication. Many individuals who have been using facilitated communication for years now have transitioned to independence. This means they no longer need physical touch to type their thoughts. These same individuals have publicly written and stated at professional conferences, that facilitated communication was the key that allowed them now to type and demonstrate their intelligence. Yet, the critics still dismiss the statements as anomalous or manipulated. Do you see the connection now between facilitated communication and the presumption of competence, or more importantly, the presumption of incompetence? Can you imagine being "smart," yet due to the inability to demonstrate this intelligence you are treated in the demeaning way that many of our bosses (consumers) are? Then, can you imagine finally finding a way to communicate and then have that method and that communication denied? Now, imagine this, you persevere and transition to independent typing, graduate high school, go to college, and pronounce that your success was due to facilitated communication, only to be told by the critics that you are simply an anomaly and would have learned to type using other methods, or worse, that your thoughts are still being manipulated by others. Can you imagine? In fact, there is no need to imagine. Read in this publication Sue Rubin's story. Talk with Sue, Eugene, Peyton, Annie, Lucy, Sharisa, and others, they will tell you the same.

Some would say that the ultimate social validation of facilitated communication can be judged by whether or not the user of the facilitated communication method has, over time, experienced a higher quality of life than before using facilitated communication. Let's take a look at some data from a 1998 study (Cardinal) where over 800 people reported their perceptions of changes in the quality of life of those who use facilitated communication. The survey respondents were professionals and parents who knew well the facilitated communication user about whom they were responding. The results of this national survey concluded that there was a statistically significant increase in the quality of life of those who use facilitated communication compared to their quality of life before they began to use FC. The focus of the study was to measure whether users of the method were perceived to have experienced changes in quality of life across a dozen life domains. For the 887 facilitated communication users from across the country whose quality of life was reported through the survey, a higher quality of life was clearly established with the coexistence of using facilitated communication.

Like inclusion, transition, and behavioral supports, facilitated communication has come a long way in the past decade or so. We know more about facilitation than ever and for many it has changed their lives dramatically for the good. It is a complex time for facilitated communication users (it has always been a complex time for them). Hundreds of people around this country are being denied the right to use facilitation — even in cases where highly trained facilitators are present and clear best practices exist. Even when the person has been using facilitated communication successfully, in many cases, they are still being denied its use. There is no justice when someone is denied a method best suited for them. In fact, to be denied the appropriate communication system is illegal, immoral, and unjust. It is with this lens that I ask for you to re-examine facilitated communication, to look beyond rhetoric, to look toward studies that are searching for new ways to examine this phenomenon, to listen to the voices of those who have experienced facilitation personally, and most importantly, to presume the competence of all individuals regardless of evidence. What do you have to lose?

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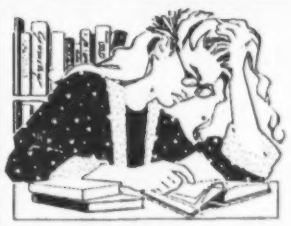

Matching a Thinking System to a Student

BY SUE RUBIN

The title of this article might appear strange to the reader, but it is quite intentional. When I was a child, I was not able to think because I did not have a method of communication. After asking other people with autism about this, I have found that about half of the nonverbal people with autism I questioned felt the same way. We were extremely limited by our lack of a communication system that worked for us. We quite wrongly were assumed to have mental retardation because we couldn't even master a simple picture system of communication.

Whether one was able to think before being able to communicate or not is a moot point because uncommunicated thoughts are nonexistent to the world beyond one's own mind. Whether the communication system meets the needs of the individual is terribly important. The problem arises when a person's intelligence is based on his ability to communicate. If he can't express his thoughts, it is assumed he is retarded and doesn't have the need for a communication system that allows for sophisticated thought. The person who has not developed a thinking process will never be able to, and the person who can't express his thoughts will be thought not to have any.

These thoughts are mine and I can only share them with the reader because I have been taught how to type. I was not able to access a computer keyboard myself like decidedly more able people with various disabilities. Every student should be assessed by a speech pathologist who has expertise in augmentative and adaptive communication devices. If he is successful that is wonde ful; however if he is not successful, facilitated communication should be taught. The current popularity of picture communication really unleashes assumptions about intelligence. It is quick and might be appropriate for a very young person, but is extremely limiting for others.

The technique that was taught to me was developed by Rosemary Crossley in the 1970's and 1980's. Great strides have been made in teaching people ways to become independent typers. It took me five years of typing with physical support before I had the control and confidence needed to be able to type without support. I still require a facilitator to sit next to me to keep me focused. Rest assured I type my own thoughts whether someone rests a hand on my arm for speed or not. Many students who are learning facilitated communication today are becoming independent typers in much less time. With practice they will be able to do grade level work by themselves so no one can deny their intelligence.

When a communication system was found that suited me, my life changed completely. I was educated erring on the side of mental retardation. When the school psychologist tested me, I scored in the range of severe retardation and certainly functioned in that range as well. When I was thirteen, I had the cognitive and adaptive skills of a two-year-old and probably have not progressed much with adaptive skills since then. I am now twenty-three and a student in Whittier College, but I still present as a person who others would label as someone with mental retardation. Just because I may look and sound a specific way, people assume the stereotype -- they assume I lack intelligence. Even though I still receive really pitying looks from strangers, I have learned to live with them and enjoy the rich life I have.

Beginning when I was thirteen and was taught facilitated communication, the school world and my family recognized my intelligence and treated me quite well. When I was fully included in high school, I took honors and advanced placement classes with really few accommodations for my disability. The teachers and other students respected my intelligence and were really patient with my autistic-like behaviors. Because I was able to communicate I was not only able to do grade level work, but I could communicate with my peers who learned how to be facilitators.

I graduated with honors and took the SAT, scoring 1370. With strong teacher recommendations and a 3.98 GPA, I was accepted to Whittier College as a John Greenleaf Whittier scholar. The professors enjoy having me in classes because I am always prepared and offer a unique viewpoint in class discussions. The only accommodations I require are extra time on tests and occasionally an alternative assignment if I am physically unable to do what the other students are doing.

The truly best part of my life is that I have friends. One of these friends was a fellow honor student at Whittier High. She has been working as a care provider for me for about five years, but spends a lot of her free time hanging out with me. My other friends are people who began as care providers, supporting me either at school or at my home, since I live off campus with a support system to enable me to live as independently as possible. My staff got to know me as an adult who has autism, but otherwise is quite like them. Basically I am able to type independently with all of the young adults with whom I spend my time. They are able to realize I have a sense of humor even though my facial expressions don't show it. They really are great friends who take me with them to parties with their friends who have become my friends.

Having a communication system that meets my needs has opened the world to me. The academic subjects I have been exposed to in high school and college have truly expanded my understanding and appreciation of the world around me. Socially, my communication system has truly proved invaluable. Without it I would still be a "non-thinking" person wrapped up in autism instead of the intelligent person I am, who is thoroughly enjoying life in spite of a significant disability.

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Some say its idealism. We say it is our right, our dream, ***Our Quest: Opportunity, Equality, Justice***. The idea that individuals should have the opportunity for a fulfilling life of their own choosing was born long ago. Our earliest leaders understood that freedom and choice are the cornerstones of the community, and the key to fulfillment and success for all. Though certainly not a revolutionary idea anymore, far too many people labeled with disabilities are still struggling each and everyday for the right to life, liberty, and the pursuit of happiness.

The TASH Conference is the modern day "Tea Party" Much like this famous event, the TASH Conference mobilizes vast numbers of people, linking folks from around the world together in a common experience of mass popular insistence - Equality, Justice and Opportunity for ALL!. The electrifying information and energy generated at the conference spreads; participants returning home with renewed spirits to stage similar acts of resistance and insistence of their own!

Over 2500 patriots of the movement for inclusive communities will gather at the TASH Conference in Boston on December 11th to share strategies, renew commitment, and create a synergy surpassed by none. BE THERE.

Sheraton Boston Hotel
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Direct Phone/Reservations: (617) 236-2000 Fax: (617) 236-1702
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The Sheraton has confirmed the following group rate, available to TASH Conference attendees:

Single Occupancy (one person) $145.00 **Double Occupancy** (two people) $153.00
$20.00 per night for each additional person
Applicable Boston Sales Tax - 12 45%

The Sheraton will accept reservations under the TASH block at the above rate, subject to availability. Once the Sheratons sells out the TASH block, or after Monday, November 11, 2002, the rates may be higher. The TASH Conference is a well-attended, popular event - so make your reservations early!

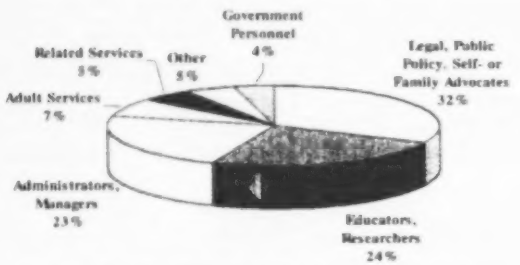
Focus on Technology

TASH annual conferences have always featured the latest in cutting edge information designed to empower individuals with disabilities to develop the hands-on skills necessary to live, work and participate independently in the community. This year, TASH is placing a special emphasis on the role Assistive and Adaptive Technology products and services play in the quest for Opportunity, Equality, and Justice.

The 2002 TASH Conference is featuring a technology section in the Exhibit Hall; a showcase of 508 technology at an evening reception; a breakfast sponsored by technology leaders; and a special technology-focused issue of our monthly news magazine, TASH *Connections*.

For more information, contact Priscilla Newton
pnewton@tash.org

Conference Attendees by Occupation or Area of Interest



The TASH Conference is the largest and most progressive gathering in the United States that focuses on the full inclusion of people labeled with disabilities. Join over 2500 people from around the world and across the street for whom the saying *All Means All*, are words to live by; a true melding of people who have successfully put the belief of inclusion for all into practice.

The deadline for TASH Call for Presentations has passed, however we are still accepting poster and roundtable luncheon proposals.

TASH Early Bird Registration

TASH Office Use Only
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Register before August 15th and Save!

- **Fill out one form for each person attending**
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  Baltimore MD 2120[illegible]
- **TASH Federal Id # [illegible]0160220**
- **All advance registrations need to be received in the TASH office by November 22, 2002. After that date registration is on-site only and will be subject to a $40.00 additional fee.**

Fax: (410) 828-6706

Questions? 1-800-482-TASH (8274) or 410-828-8274;
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Accommodations needed:

If you are not a current TASH Member, JOIN NOW for $88 for Individual or $45 for reduced rate (income less than $25,000)
This special offer entitles you to register for the conference at the member rate, and includes one-year membership.

Discount rates until 8/15/02

New or Current TASH International Members Column A

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[ ] I am joining or renewing now

International →	**$88 or $45**
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Individual Registrant	**$219**
Family Member or Person with a disability	**$39**
Personal Assistant *	N/C *
Student	**$129**
One Day Only [ ] Thursday [ ] Friday	**$119**
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TASH Chapter Only or Non-Members Column B

← Join TASH And Save!

Circle One

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Personal Assistant *	N/C *
Student	**$219**
One Day Only [ ] Thursday [ ] Friday	**$179**
Saturday Only	**$69**

*(*Personal assistants must attend sessions and register at the same time with the individual for whom they are providing support to attend conference activities) Please use a separate form, and send the forms in together.*

Team Discounts (must register together):

- Groups of 5 or more registering at the same time OR
- Two or more members of the same team (i.e.: a special educator and a regular educator)

Subtract $20 per registrant for group or team discount if applicable. **(Please take only one discount)**

	Subtract Discount Here→	-		Subtract Discount Here→	-

TASH TECH Pre-Conference Workshops 10:00 AM- 4:00 PM, Wednesday, December 11th
(registration is in addition to the conference fees)

Pay now and choose later (we'll send you the choices when they are published)

	TASH Member	+$55.00		Non-Member	+$85.00
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Round Table Networking Luncheon – Thursday, 1:00-2:15 PM
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I would like to make a donation to support a self-advocate/parent to attend the conference:

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Registration will not be accepted without payment by check, credit card authorization or with an official purchase order. Payment must be in U.S. Funds only. A $25.00 processing fee will be deducted from all requests for refunds that are received before October 15, 2002. No refunds after that date. $25.00 fee for returned checks or unauthorized charges.

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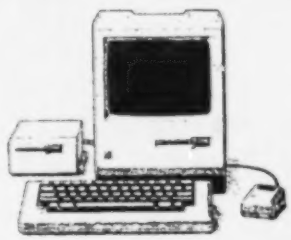

Assistive Technology Should Empower, Not "Help," People with Disabilities

BY LAURA HERSHEY

Ryan Fatterson, a high school student from Grand Junction, Colorado, has been getting a lot of attention over the past couple of months. This bright young inventor has won several big-money competitions — such as the Intel International Science and Engineering Fair and the Siemen's Westinghouse Science and Technology competition — for developing something he calls a "Sign Language Translator." It's a golf glove fitted with wires and a computer chip. Impressed reporters echo Patterson's enthusiastic claim that the device "translates sign language to printed text."

But that isn't exactly true; the device's name is a misnomer. It doesn't translate American Sign Language, which is a fully-developed language complete with an enormous vocabulary, sophisticated syntax, and complex grammatical and stylistic conventions. Instead, it converts finger-spelling, the alphabet of 26 letters, into electronic text readout.

In numerous media interviews, Patterson has stated that he initially got the idea for the device when he saw some deaf people in a Burger King ordering food through a sign language interpreter. Here's how the Denver Post described the scene:

"He watched as a teenage girl used sign language to tell an adult translator what she wanted to eat. The translator then had to order for her. 'How awful,' Patterson thought. As a teenager, he felt sorry for any teen who would always need an adult translator tagging along. And as a science whiz, he recognized there was wasted cost and effort in having a human translator. He knew there was an electronic solution."

Pity, not necessity, was the mother of this invention. Never mind that both Patterson and the Post reporter got it all wrong: Interpreters don't "order for" — or speak for — deaf people. They simply facilitate communication by, yes, interpreting! Interpreters don't represent "wasted cost and effort" — they provide access.

The invention unquestionably represents an amazing technical achievement. From a scientific point of view, he no doubt deserves an "A." Culturally, however, the invention makes no sense. Sorry, Ryan. First of all, finger-spelling is not equivalent to American Sign Language (ASL). Deaf people whose first language is ASL will have to translate their own thoughts into English, and then spell out each word letter by letter — a cumbersome way to communicate. Secondly, the glove can "translate" only one side of a conversation. A deaf person using the glove to ask a question could not expect an answer.

People with disabilities know their own needs. We must be the ones to decide what technology can and should do for us. Researchers and inventors should collaborate with us to develop the technology that we can use, rather than forging ahead with a new product that we may not want or need, just because they're smart enough to do so.

The most effective, reliable, efficient way for deaf and hearing people to communicate with each other is through a skilled sign language interpreter. Of course, interpreters may not be immediately available. In some situations — medical emergencies and criminal justice encounters, for example — it's crucial that an interpreter be brought in as soon as possible. In more casual, simple interactions, like ordering a hamburger, deaf and hearing people can get their points across by writing notes — a far better method than the unidirectional communication involved in the wrongly-named "Sign Language Translator."

In an interview on Colorado Public Radio, Patterson said he realized, in that fast-food restaurant, that people who don't speak cannot be independent. Wrong. Independence comes from choice, control and responsibility, not from doing everything unassisted.

During the same interview, Patterson said that he did not have any deaf friends or family members; nor had any deaf people tried using the device. He said he was planning eventually to test the device with some deaf people. I guess the product's usefulness — or lack of same — to the people it was designed for was not an important factor in the judges' evaluations.

To date, Patterson has won over $300,000 in scholarship money, for a device which will benefit deaf people very little, if at all. That happens far too often in the "real" world of assistive technology research and development. Federal dollars pour into university-affiliated laboratories, supporting mostly nondisabled scientists in developing technology to "help the disabled." They pursue all kinds of ingenious ideas, but are not always guided by disabled people's stated needs, goals, or values.

This young man's naivete would not bother me so much, except for two things. One, journalists exhibit even greater naivete by accepting and amplifying Patterson's uninformed assumptions — without even bothering to find so many career scientists a

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Assistive Technology Should Empower, Not "Help," People with Disabilities

Continued from page 20

exhibit the same tendency to develop technology "to help disabled people" without basing their research on any genuine understanding of the community they hope to assist.

In September I attended a small conference in Canada about technology design and disability. I saw several impressive presentations of exciting, innovative projects, which involved engineers and scientists working closely with people with disabilities to develop new tools. A good example: researchers at the University of Washington were contacted by a man with Parkinson's. He explained that his neurological impairments prevented him from walking. He had discovered that markers placed on the floor, at regular intervals, provided him with the visual cues he needed to place one foot in front of the other. So, he reasoned, perhaps a device could be developed that would simulate those floor markers.

He approached the University researchers with this idea, and over the next several months, they worked closely together to design a pair of glasses which would project lines in the wearer's visual path. The project was initiated by a person with a disability, and it ultimately benefited him by giving him more control over his environment. It has also yielded benefits for other people with similar conditions.

At the other end of the usefulness spectrum, I saw several projects which seemed to have evolved in a complete vacuum. One involved life-sized puppets dancing on a stage, which could be controlled via computer by people with disabilities sitting at home. Why? Don't ask me! (I asked the designers whether any people with disabilities had been involved in conceiving, designing, or governing this project. No, they hadn't. But the developers assured me that they would be testing it with some actual people with disabilities real soon.) People with disabilities know their own needs. We must be the ones to decide what technology can and should do for us. Researchers and inventors should collaborate with us to develop the technology that we can use, rather than forging ahead with a new product that we may not want or need, just because they're smart enough to do so.

The Bush Administration has proposed a major increase in funding for assistive technology development. The president's "New Freedom Initiative" proposes $1.1 billion in funding to promote employment of people with disabilities, and much of this money focuses on assistive technology. For example, his budget requests $20 million in funding for Rehabilitative Engineering Research Centers to conduct research on specific technologies; $3 million for the Interagency Committee on Disabilities Research to coordinate government-sponsored assistive technology research and development; $5 million for the Assistive Technology Development Fund to underwrite small businesses in doing technology demonstration, testing, and market research; $40 million for low-interest loans to assist people with disabilities in buying assistive technology; and so on.

As disability programs go, assistive technology tends to be popular among conservatives and liberals alike. It seems almost magical in its flashy efficacy. Besides that, it's a comfortingly individual solution: Put the right gizmo in the hands of a person with any given disability, and Presto! Instant equality.

I have to admit I'm a pretty big fan of assistive technology myself. I love the power my voice-activated computer and my sip-and-puff wheelchair give me. I want those researchers to keep developing more and better devices.

But in inventing and refining those devices, researchers must consult with, and be accountable to people with disabilities. All those millions of dollars the Federal officials offer to universities and businesses should come with firm requirements for governance by disabled users of assistive technology.
I hope young Ryan Patterson puts all that scholarship money to good use: I hope he goes to college and graduate school, and follows his career goals as far as everyone expects. And I hope the next time Ryan designs an invention for "helping people," he'll first talk to the people he's trying to help.

Laura Hershey is a disability rights leader, poet, writer and trainer. For more information on Ms. Hershey's work, please visit her web site, http://www.cripcommentary.com

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Position Statement on Access to Communication Services and Supports:

An Update from the National Joint Committee on the Communication Needs of Persons with Severe Disabilities

Submitted By

Lee K. McLean, University of North Carolina-Chapel Hill; Beth Mineo Mollica, University of Delaware; Pat Mirenda, University of British Columbia; Diane Paul-Brown, American Speech-Language-Hearing Association, Mary Ann Romski and Rose Sevcik, Georgia State University; and Martha E. Snell, University of Virginia

[Authors' Note: The following article was adapted from material published in a combined American Speech-Language-Hearing Association newsletter for the members of SID #1 and SID #12.]

Background and History of the NJC

In 1985, the U.S. Department of Education and The Association for Persons with Severe Handicaps (now TASH) co-sponsored a national symposium on communication by individuals with severe disabilities. A series of consensus statements regarding issues and needs were identified during the course of the meeting (OSEP & TADS, 1985). One consensus statement recommended the establishment of a multi-disciplinary committee to address the many needs and issues identified during the symposium. In proposing the establishment of this national joint committee, the symposium participants acknowledged the essential roles played by professionals from many different disciplines in the delivery of appropriate communication supports and services for persons with severe disabilities.

Following the symposium, invitations were sent out to a number of associations whose members included professionals involved in services for children and adults with severe disabilities and/or communication disorders, to join this new National Joint Committee (NJC) for the Communication Needs of Persons with Severe Disabilities. The purpose of the NJC was and still is to promote research, demonstration programs, and in-service/preservice education to help persons with severe disabilities communicate effectively.

Over the past 17 years, organizational membership on this joint committee has remained relatively stable. Today, member organizations include: the American Association for Mental Retardation (AAMR), the American Occupational Therapy Association (AOTA), the American Speech-Language-Hearing Association (ASHA), the Council for Exceptional Children-Division for Children with Communication Disorders (CEC-DCCD), the U.S. Society for Augmentative and Alternative Communication (USSAAC), the Rehabilitation Engineering and Assistive Device Society of North America (RESNA) and, of course, TASH, one of the founding organizations.

The first major project of the National Joint Committee was a three-pronged effort that included the development of (a) a "Communication Bill of Rights," (b) a set of recommended assessment and intervention practices, and (c) a list of essential knowledge and skills for teams serving individuals with severe disabilities. These documents were endorsed by the Executive Boards of all member associations and were subsequently published in an ASHA policy supplement (National Joint Committee for the Communicative Needs of Persons With Severe Disabilities, 1992).

In 1992, a meeting entitled the "National Symposium on Effective Communication for Children and Youth with Severe Disabilities" was sponsored by the U.S. Department of Education. At this symposium, keynote speakers commented on the significant gap that still existed between recommended and actual practices in the delivery of communication supports and services for individuals with severe disabilities. In an effort to help close this gap, NJC members began work to develop a self-assessment instrument to translate the principles and practices described in the 1992 guidelines paper into a more concrete set of quality indicators. The resulting Communication Supports Checklist for Programs Serving Individuals with Severe Disabilities (McCarthy et al., 1998) is now available for use by interdisciplinary teams in a variety of service settings and agencies.

Position Statement on Eligibility for Communication Services and Supports

Since 1999, NJC members have devoted themselves to the development of a position statement addressing issues affecting eligibility for communication services and supports. This emphasis emerged in response to ongoing and disturbing reports that educational and health care agencies often deny such services to individuals with severe disabilities for a variety of reasons, including age, severity of disability, a lack of purported prerequisite skills, and so forth.

Early in the fall of 2001, the NJC submitted a draft position statement and report on

Eligibility for communication services and supports should be based on individual communication needs. Communication services and supports should be evaluated, planned and provided by an interdisciplinary team with expertise in communication and language form, content, and function, as well as in augmentative and alternative communication (AAC).

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Position Statement on Access to Communication Services and Supports

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eligibility policies to a peer review process involving representatives from all member organizations as well as other invited reviewers (including professionals, parents, and persons with severe disabilities). From October, 2001 to January, 2002 revisions were made to the draft document to address comments that resulted from the review process. Since January, 2002, the revised position statement has been submitted for endorsement to the executive boards of all member associations (AAMR, APTA, AOTA, ASHA, CEC-DCCD, USSAAC, RESNA, and TASH). So far, both AAMR and TASH have endorsed the position statement and have posted it on their organizational web sites.

The core position taken by the NJC in the document is as follows:

POSITION

It is the position of the National Joint Committee for the Communication Needs of Persons with Severe Disabilities that eligibility for communication services and supports should be based on individual communication needs. Communication services and supports should be evaluated, planned and provided by an interdisciplinary team with expertise in communication and language form, content, and function, as well as in augmentative and alternative communication (AAC). Decisions regarding team composition, types, amounts, and duration of services provided, intervention setting, and service delivery models should be based on the individual's communication needs and preferences. Eligibility determinations based on a priori criteria violate recommended practice principles by precluding consideration of individual needs. These a priori criteria include, but are not limited to: (a) discrepancies between cognitive and communication functioning; (b) chronological age; (c) diagnosis; (d) absence of cognitive or other skills purported to be prerequisites; (e) failure to benefit from previous communication services and supports; (f) restrictive interpretations of educational, vocational, and/or medical necessity; (g) lack of appropriately trained personnel; and (h) lack of adequate funds or other resources.

In the extensive text accompanying above statement, arguments are presented to refute each of the eight "criteria" cited in the paper that are often used to deny access to communication supports and services. The arguments are based primarily on the extant research literature related to communication intervention in general and augmentative and alternative communication interventions in particular that have been used with persons with severe disabilities. We believe that the NJC document will be an extremely useful tool for TASH members and others who continue to fight for high quality and effective communication services and supports for persons with severe disabilities.

The full position statement and accompanying document (approximately 23 pages) is available on the TASH website (http://www.tash.org/communication/comneeds.htm) and will soon be available on a new NJC website as well. Watch for an announcement of the NJC website address in an upcoming issue of TASH *Connections*!

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Alameda Unified School District

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Required: Valid Appropriate California Teaching Credential; Experience with students with autism spectrum disorder and/or behavior challenges
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- Participate in SELPA Autism Steering Committee
- Serve as liaison and consultant to other professionals, agencies, and community.

Resumes or letters of interest may be submitted to Alameda Unified School District, 2200 Central Avenue, Alameda, CA 94501, Attention: Personnel Department, or contact Personnel at (510) 337-7070.

Teach in the Area of Moderate/Severe Disabilities

California State University, Northridge has two federally funded projects in the area of teacher training.

Project SOS: Supporting Our Students helps teachers earn their Level I California Preliminary Credential in Moderate/Severe Disabilities. Project SMART: Support Through Mentoring, Assistance and Resources for Teachers helps teachers with a preliminary credential earn their Professional Level II Credential in California with a MA degree.

Both programs provide financial and mentored support for those interested in working with students who have been labeled with moderate, severe and/or multiple disabilities in inclusive educational settings.

Courses and fieldwork experiences are designed to provide teachers-in-training with the necessary skills and knowledge to facilitate the inclusion of students with severe disabilities in general education settings while providing a meaningful and functional curriculum designed to meet each student's unique needs.

If interested in this program, contact Dr. June Downing at 818-677-5261 or send an e-mail to june.downing@csun.edu

Thank You!

TASH's work is dependent on the financial assistance of our donors and members. We wish to acknowledge the generous donations of the following individuals:

Dr. Paul Alberto
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Donna DeStefano
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Continued from "Perceptions of FC," *page 16*

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Seek Out Opportunities Where Communication Can Happen

BY PASCAL CRAVEDI

In many ways, this is an exciting time in the world of augmentative/alternative communication (AAC). There have been tremendous advances in the technology of communication devices over the last ten years. Individuals with communication disabilities have available to them a number of different options for communication methods to use. Speech language pathologists are gaining greater levels of expertise with AAC. All these developments are contributing to greater opportunities for communication for non-speaking individuals. However, the development that may have the greatest potential for creating better supports for communication is the increased presence of individuals with communication disabilities using their communication systems in community and social settings.

Whether it is someone using his/her voice output device to order food in a restaurant or using one to make a presentation in a public forum, individuals with communication disabilities are making their voices heard and in the process, changing perceptions about the abilities of non-speaking individuals and increasing awareness about communication as a basic human right. As examples of this development, I want to share the perspectives of several Vermonters that I have met, all of whom use AAC. I also want to highlight the important role of their communication partners. This role involves not only training them to use their communication systems, but also facilitating opportunities for them to communicate in situations which enhance their community participation and social interaction.

Most recently, Troy Daniels, a student at Northfield High School in Northfield, Vermont appeared at a public forum to discuss maintaining funding for developmental services in Vermont at the Vermont State legislature. Troy gave a speech using his Dynamite communication device to advocate for maintaining funding for services for individuals with developmental services in Vermont. Troy was one of the few people who used other than a method of communication speech to provide testimony to state legislators. Who is Troy? This is his story in his own words:

"My name is Troy Daniels. I live in Northfield, Vermont. I am a person with a disability. I am in grade 12 in my town high school. One of my disabilities is that I do not use my voice to speak, I use a Dynamite (voice output device). I call her 'Libby.' I have had other Libbys before; they all work different. That is hard. When the school thinks I should have a different Libby, I have to try to learn a new 'language.' This is how it feels to me. I like this Libby the best. I think that is because this time the school hired a person to work with me. Her name is Julie and she knows how to teach me to use Libby.

Before this Libby, I would try to change what people talked to me about because I could only say a few words. No one liked to talk to me about the same thing all the time. Now when I use Libby, I can talk about anything I can type. Now people know that I am smart, and that I can think like they do. They are surprised. I am not surprised; I always knew I could think good.

I have all the friends. My friends ask to learn how to help me with Libby. One friend is working with Julie so he can make sure that I can say all I need to say. He is on the hockey team and I am the manager, he knows that I am smart and he wants all the team to know that I am smart.

Most times it is hard with adults because they do not know how to use Libby, so they say I do not need to use Libby. They say that they understand my voice, but they do not. My friends and my parents are the ones who get it. They know I need Libby, and they help me to know why I want to use Libby.

Last month I wrote a speech with my Mom asking the State to give more money to help people like me. My Mom helped me put the speech in Libby, and I went to the State House and I stood up in front of a huge crowd of people and I said my speech. Everyone clapped and clapped. I feel like a real person. Everyone should feel like a real person."

Sarah is another person I know who has had impact on increasing awareness about the importance of communication. She currently lives in Montpelier, Vermont and receives day support services from a local developmental services agency. She has been using facilitated communication (FC) for more than 10 years, and has certainly experienced her share of successes and frustrations with access to communication.

Technology, expert consultation, therapy, and financial resources are definitely critical elements in the support system for a person with a communication disability but perhaps, most importantly, are the opportunities to be a part of everyday life in school and in the community.

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Seek Out Opportunities Where Communication Can Happen

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She is a persistent person with strong opinions, and has taken on a self-advocacy role both locally within the agency from which she receives services and also statewide in her role as a self-advocate representative on an advisory board to the commissioner of the Vermont Department of Developmental and Mental Health Services. In this role, she is frequently asked to give her input on policy and budget issues related to the developmental service system in Vermont. Her case manager, Amy McDonald, who has accompanied her on many occasions to her meetings, describes Sarah's impact on others in this way: "After they see her communicate through FC, she becomes a person to them, and they are suddenly uncomfortable not just with the way they have judged her, but perhaps with the way they have viewed other people as well." In talking with others about the importance of communication, she frequently shares this personal story:

"I started using FC (facilitated communication) a long time ago. Talking is hard for me. Sometimes the things that I say aren't the real thoughts that I want to say. Only when I have trained facilitators can I have real conversations. Before I had typing, people thought I was stupid. I freed my mind from autism with typing.

"Communication can't happen in a vacuum. Communication happens in that vital pulsing web of social interactions that is part of most of our daily lives. Whether we are at home, at work or at play, we spend a good part of our day talking to people.... Everybody wants to be in the mix."

Talking to my parents has been hard all my life. Now talking is easier because watching my words be typed answers for them the real question of my intelligence. Using typing lets me be a person; I really want to have people see the real me. I have been able to tell people how I feel and what I want.

I try to help other people now. Using FC has saved my self from boredom. I don't want to be stuck in myself any more. Instead of being just me and no one else, now I can bring others into me. They can understand me and I can understand them. Asking for the things I want gives me freedom.
I need certain things to communicate. I need a board or device to type on. I need trained staff who stay in the job for a long time. They need lots of training and practice. It is very hard to have only one facilitator. But it's worse to have none.

[Support staff] should get rewarded for wanting to learn about communication. It is hard and takes a long time. We need new facilitators to be trained all the time, or we will run out. We need lots of people to care about communication. It has been pretty hard, but always it has been worth it."

Laura is a middle school student in the Burlington, Vermont area. She communicates through speech and facilitated communication (FC). Laura has many goals for herself around communication, including being able to type independently and to talk more. She works daily on her speech with her speech/language therapist in therapy sessions, and practices using it throughout her day in many different ways — from expressing choices to reading out loud things she has typed with FC.

Recently, she got up in front of her class and read out loud portions of a paper she had written on dolphins. This was an exciting moment for her because initiating speech and coming out with the right words has been a great challenge for Laura. She writes beautiful poetry, both serious and humorous, particularly about herself. Here is a humorous example:

"See that monkey in that tree?
Just how smart you think he be?
He can swing above your head
And think about [what] you just said.
So don't think monkeys cannot feel or you may slip on a banana peel."

Nicole Edgerly is a young adult living in the Burlington, Vermont area who recently acquired her first electronic communication device and is beginning to experience the excitement of having her voice understood by others.

"My name is Nicole Edgerly. I have this LINK talk for me. People have a hard time understanding me when I talk. When I was very young, I used hand signals to let people know what I wanted. I got help with my speech in school. Support from my family and friends helped. They were patient in listening to me. With the LINK, people understand me much better. I answer questions at our bible meetings now. I feel much better talking now."

Although it is never easy, Troy, Sarah, Laura and Nicole are beginning to experience the excitement of being able to communicate their thoughts to others. Their successes have occurred through a combination of their own determination and courage and the support of others around them. Perhaps Sarah said it most simply and clearly when she said, "We need a lot of people to care about communication."

All of them have a circle of people around them that care deeply about their communication, and work hard to provide them with the training and support they need to communicate successfully. Troy has a parent who can advocate strongly for his communication needs and help him to use his communication device. Beyond the immediate circle of his family, he also has friends at school who understand his communication system and can help him use it.

Laura has similar support across home and school. Her presentation on dolphins was very much a team effort involving not only her educational assistant, Ali, at school but also her parents at home. Whether it was

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Seek Out Opportunities Where Communication Can Happen

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preparing the text for her presentation or rehearsing the words that she would say in her class presentation, each had a role in helping her to prepare her assignment.

With the support of family, her case manager and her job coach, Nicole will continue to expand her use of the LINK. Soon she will be learning to use it at her job to have conversations with her co-workers. This will be a coordinated effort involving her case manager, job coach and communication specialist.

Obviously, not every person with a communication disability is as fortunate to have the kinds of support that Troy, Sarah, Laura and Nicole have. But I would hope that their visible presence in public settings is laying the foundation for supports for people with communication disabilities to be broadened beyond the circles of service providers and professionals to community members.

Hillary Clinton uses the African proverb, "It takes a village to raise a child." Certainly, this could apply to assisting people with communication disabilities. Technology, expert consultation, therapy, and financial resources are definitely critical elements in the support system for a person with a communication disability but perhaps most importantly, are the opportunities to be a part of everyday life in school and in the community.

In an article titled, *Time to Get in the Mix*, from his publication, Alternatively Speaking, Michael Williams speaks to the importance of communication happening in everyday, social situations:

"Communication can't happen in a vacuum. Communication happens in that vital pulsing web of social interactions that is part of most of our daily lives. Whether we are at home, at work or at play, we spend a good part of our day talking to eople...Everybody wants to be in the mix. But for those of us with communication disabilities, it's not easy. Whether we have our disabilities at birth or acquire them later in life, communication disabilities have the same effect: they take you out of the mix. You are a spectator, half hidden in the corner. Even if you want back in, you are probably too scared, because communicating when you have a speech disability means taking risks...I have news for you. The only thing keeping you from getting in the mix is your own fear of what you think might happen. Come out of the shadows. Peek around the corner. There's a party going on and you're invited."

Michael Williams acknowledges the risk involved for the person using AAC, but is clear that the only way for people with communication disabilities to make communication meaningful is to get out into the mainstream of community life. The benefits of "getting in the mix" outweigh the risks. Troy took the risk of getting up in front of a packed room to express his concerns about potential funding cuts. What if something went wrong with his device? Laura took the risk of reading her paper out load. What if not all the right words came out? Sarah has taken the risk of using facilitated communication in public forums where skeptical people might question the authenticity of her communication. Nicole is beginning to learn to use her LINK device in different situations and is taking the risk of trying a different way of communicating from others that she has relied on for many years.

Laura addressed the issue of risk taking when she wrote this personal reflection for a recent school assignment on the Jack in the Beanstalk story:

"I am like Jack because I am bold. He takes risks so he can survive. I also need to take risks because I am easily challenged by many things. If I don't take risks, I remain trapped in a confusing life of autism. I am bold enough to allow myself to figure my way out of a chaotic world. If I didn't take risks, I feel I would be lost. I am isolated in a world of awesome confusion unless I decide to climb out. Climbing out of autism to heaven is a bold decision for me. Jack didn't know what he would find. I am uncertain about what I will find. but must try to climb to a better life."

The other side of the risk taking is for those of us in the role of communication partners. It is far easier and safer for us to work with an individual on using a communication system in one-to-one situations out of the public eye, and then take the lead in communicating to others in the public what a person wants. Have you ever stood in line with a person using a communication device at a McDonald's during lunch hour? Many of us have certainly experienced the apprehension about customers in a restaurant becoming impatient as we try to take the time to support a person to communicate their order. Granted, lunch hour at McDonald's may not be the ideal place to practice communication skills. But that situation illustrates the point that when we are acting as a communication partner for someone, we may need to take risks ourselves and move beyond our typical support roles. How serious an issue is it really if the line at McDonald's is held up an extra minute while someone with a communication device gives his/her order and the counter person gives the needed time and attention to finish the message?

As much as it is our role as communication partners to teach a person how to use his/her method of communication, it may be equally important to teach others how to listen to what a person with a communication disability has to say. To do so requires that we become adventurous and seek out opportunities where communication can happen in the hustle and bustle of everyday life.

Pascal Cravedi-Cheng is an Facilitated Communications Consultant with Howard Community Services in Burlington, Vermont. Comments regarding this article may be sent to Pascal by e-mail, pascalcc@howardcenter.org

TASH NEWSLETTER

Policy Statement

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TASH CONNECTIONS

Equity, Quality and Social Justice for People with Disabilities

Inside This Issue

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- Autism Inside Out: An Interview with Donna Williams
- Supporting People with Autism
- Language is More Than Speech
- Remembering Justin Dart

The Power of the Presumption of Competence:

New Ways of Understanding People with Autism

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TASH sincerely thanks the NLM Family Foundation for its generous support of the publication of this edition of TASH *Connections* and for promoting progressive understandings of people with the autism label.

Some cover photos by P. Sue Kullen and Catriona Johnson.

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TASH MISSION

TASH supports the inclusion and full participation of children and adults with disabilities in all aspects of their communities as determined by personalized visions of quality of life.

TASH's focus is on those people with disabilities who:

- Are most at risk for being excluded from the mainstream of society
- Are perceived by traditional service systems as being most challenging;
- Are most likely to have their rights abridged;
- Are most likely to be at risk for living, working, playing, and/or learning in segregated environments;
- Are least likely to have the tools and opportunities necessary to advocate on their own behalf;
- Historically have been labeled as having severe disabilities; and,
- Are most likely to need on-going, individualized supports in order to participate in inclusive communities and enjoy a quality of life similar to that available to all citizens.

TASH accomplishes this through:

- Creating opportunities for collaboration among families, self-advocates, professionals, policymakers and other advocates;
- Advocating for equity, opportunities, social justice, and rights;
- Disseminating knowledge and information;
- Supporting excellence in research that translates to excellence in practice;
- Promoting individualized, quality supports;
- Working toward the elimination of institutions, other congregate living settings, segregated schools/classrooms, sheltered work environments, and other segregated services and toward replacing these with quality, individualized, inclusive supports;
- Supporting legislation, litigation and public policy consistent with **TASH**'s mission; and,
- Promoting communities in which no one is segregated and everyone belongs.

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From the Executive Director
BY NANCY WEISS

The Power of Assuming Competence

This edition of TASH *Connections* is dedicated to an issue that TASH views as extremely important. I once asked TASH members what they thought distinguished TASH from the many other disability organizations that exist. Don Cardinal spoke for many in saying that the prevailing connection among TASH members, TASH's gift, and our unifying stance, is a commitment to social justice and the assumption of competence of all people. This edition of TASH *Connections* is dedicated to highlighting and exploring these issues as they apply to people with autism. The issue contains a broad range of articles, many expressing the views of people with autism themselves and many written by family members and people who are committed advocates of people with autism and the issues they confront.

Earlier this year, TASH began discussions with the NLM Family Foundation in Boston about an issue of shared concern. It seemed to people affiliated with both organizations that people with autism are rarely involved in national efforts toward disability rights and progressive disability policy. Together, TASH and the NLM Family Foundation set out to learn more about this issue and to pursue possible solutions.

In early May of this year, TASH held an historic meeting in Boston. The meeting was made possible through the generous support of the NLM Family Foundation. The Foundation is also sponsoring the publication and distribution of this edition of TASH *Connections*. The purpose of the meeting on May 3rd was to explore whether people with autism had an interest in being more involved in shaping public policy; if so, what the barriers were to such participation and what steps could be taken to overcome those barriers. The meeting was attended by over forty people. Represented were national disability rights and disability policy leaders, family members and a great number of people with autism, many of whom communicated through facilitated communication. Participants spent a full day together discussing the following questions:

❖ What would meeting participants like the future to look like with regard to people with autism being involved in public policy efforts?

❖ What have we learned from other initiatives or movements in which people with disabilities are at the forefront (especially People First groups, Self Advocates Becoming Empowered and ADAPT)?

❖ What are the hot public policy issues on which existing advocacy groups are or will be working?

❖ What kinds of public policy issues are most likely to be of interest to people with autism?

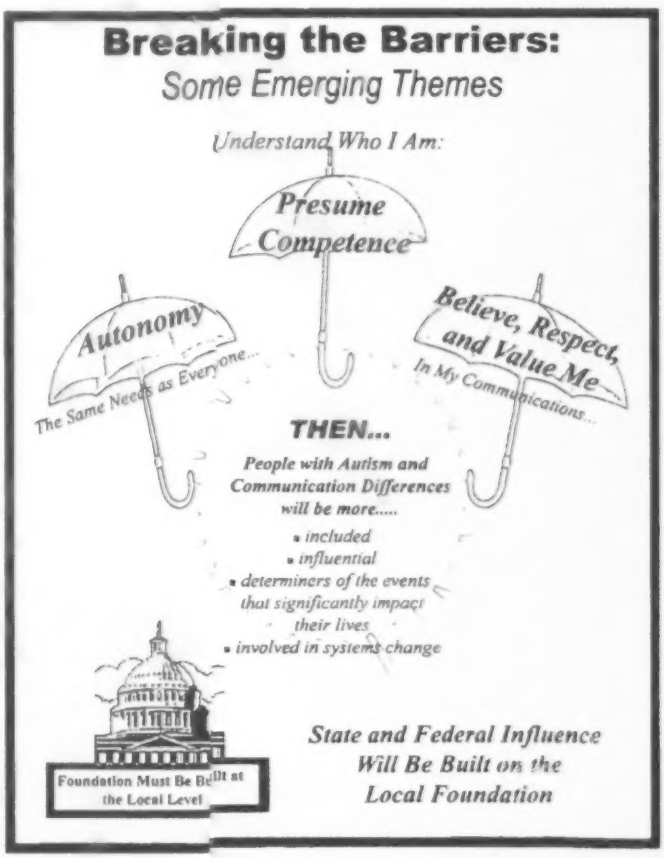
❖ What are effective strategies for influencing public policy and how does this work get done?

❖ How can people with autism/ communication differences get more involved?
- What roles do they want to play?
- What obstacles exist?
- What supports are needed?
- How can existing groups and individuals currently involved in public policy work reach out and include people with autism?

❖ What are the next steps to assure that people with autism have opportunities to participate in public policy efforts?

The meeting was a great success. The individuals with autism who participated in the meeting were clear that in their view people with autism *did* want to become more involved in effecting progressive disability policy, with proper support to assure that all individuals accessed meaningful and personally motivating opportunities for participation.

The dialogue among participants elicited an overall message which was conveyed multiple times in differing ways. Participants labeled with autism urged people who worked with them, family members, national disability leaders and community members in general to take the time to understand them better.


Breaking the Barriers:
Some Emerging Themes
Understand Who I Am:
Presume Competence
Autonomy
The Same Needs as Everyone...
Believe, Respect, and Value Me
In My Communications...
THEN...
People with Autism and Communication Differences will be more.....
• included
• influential
• determiners of the events that significantly impact their lives
• involved in systems change
Foundation Must Be Built at the Local Level
State and Federal Influence Will Be Built on the Local Foundation

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THE POWER OF ASSUMING COMPETENCE

Continued from page 3

Three major messages were communicated relevant to this desire to be understood more fully and fairly:

❊ First and foremost, the people with autism participating in the May 3rd meeting wanted people who interacted with them to presume competence -- to start with the assumption that all people have much to offer. They wanted people who do not share the label of autism to work with them to ensure that they have the same opportunitites as all citizens to be heard, to make decisions about their own lives and own needs -- to clear away the barriers of low expectations and incorrect assumptions based on initial perceptions of someone's disabilities.

❊ Growing out of this presumption of competence, they saw an opportunity to gain autonomy — as unique individuals who have individual wants and needs as well as people who may share common concerns and goals with each other and with others.

❊ Equally important, they told us that if we believe they are competent people, we will respect their ways of communicating and their requirement for assistance and support. They felt that once people valued them as competent communicators and got to know them as individuals they would listen to and respect their points of view.

From the establishment of these perceptions of people with autism as being autonomous, competent, and valued, the meeting participants saw a natural progression to opportunities for themselves and others to participate in public policy efforts and effect meaningful social change. It was felt that once these "umbrella" aspects of participation were established, people with autism who communicated in non-traditional ways would be included as influential determiners of the events, public policies and systems that significantly impact their lives.

It was agreed that the foundation for this change needs to be built first at the local level;

Eugene Marcus (left) and Mayer Shevin

that people with autism, like all participants in social change, need first to consider what changes they would like to see possible in their own lives, work to accomplish these changes within their own families, supporting agencies, and communities, and then expand their efforts to affect people and policies on broader state and Federal levels.

Some specific ideas, suggestions and outcomes from the May 3rd Meeting are listed below:

Defining the Vision ... "If dreams could come true"
❊ View people with autism as a real force
❊ Freedom is not a "special right"
❊ The ropes of political power stretch to and from people who have been labeled
❊ Find ways to describe ourselves that tie into the concerns of everyone
❊ People with autism owning their own homes; working; creating, loving and raising families; on their own terms
❊ We have to educate the rest of the world that even people who cannot speak in traditional ways can direct their own lives
❊ Don't restrict people to keep them safe -- empower them
❊ We have to guard against forced impoverishment, guardianship, and behavior interventions that have as their goal making people normal

Hot issues
❊ Everyone with a disability should get an opportunity to communicate by whatever method best serves them
❊ Self-determination, community and educational inclusion, real jobs
❊ Getting people out of institutions
❊ Better oversight of quality of FC practice; access to trained facilitators and more financial resources to support facilitation
❊ More education equals more leadership and power
❊ Poverty and its consequences are one of the biggest problems
❊ There needs to be research in which people with autism are the primary investigators
❊ The language of self-determination has been hijacked by people who say the words but do not follow through or have the values (like choice, inclusion, participation...)
❊ Perceptions are based on today's reality - people with significant disabilities are not at the table.

Barriers
❊ Transportation and accommodations
❊ FC lacks professional support, it is de-legitimized
❊ Not enough money for social change work
❊ Stigma and bigotry
❊ People with autism are not being taken seriously
❊ Initiating is hard
❊ Segregation, protective environments, guardians and payees stand in the way of autonomy and freedom

What do we do about barriers?
❊ People with autism need to be on boards and in leadership positions
❊ Increase understanding about different ways of communicating
❊ Counteract stigma and negative images

Pascal Cravedi (left) and Larry Bissonnette

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"We need to share our emerging understanding with those who are willing to listen"

BY A.M. DONNELLAN AND MARTHA R. LEARY

We are pleased to be included in this special issue of *Connections* which is intended to increase the disability community's understanding of the abilities and potential contributions of people with autism and communication differences. Both of us have had the privilege of knowing many people labeled with autism, and their families, from the time they were labeled through childhood and into adulthood. Our friendships and alliances with people have inspired us to examine how the research literature on autism has both helped and hindered us in our efforts to understand people with the autism label.

Over the years research has certainly helped the world shift from of a view of autism as a form of psychosis caused by poor parenting to one which recognizes the developmental nature of the condition. It has also provided broad outlines of possible causes and treatment approaches, albeit with little consensus and much controversy (see Bristol, et al, 1996 for a review).

Despite the controversies and disagreements among various theoretical schools or camps, the opinion of many in mainstream circles is that autism is a condition that is well understood (e.g. Jacobson, Mullick & Schwartz, 1995). In fact, the scientific literature has delineated numerous deficits that are meant to both define autism and explain the behavior of the child or adult carrying that label. As a result, when a parent asks: "Why does my child rock and spin and echo?" the answer may be little better than: "Because he has autism." The parent follows up with: "How do you know he has autism?" The answer is: "Because he rocks and spins and echoes." The very characteristics used to define autism merely label that which we do not yet understand (Donnellan & Leary, 1995). Ultimately, this contributes to a situation in which we believe we know more than we actually do (Donnellan, 1999).

For example, the standard description of autism available to physicians, researchers and parents, the Diagnostic and Statistical Manual of Mental Disorders or DSM IV (APA, 1994), applies a social context to people's behavior by using terms such as "failure to"; "prefers to"; "unusual interest in"; and "lack of spontaneous seeking to share enjoyment." Such descriptions lead us to believe that it is possible to understand the internal motivation and mental processes of people who communicate and relate to others in an unconventional manner (see Donnellan, 1999). Further, these descriptions fail to acknowledge the possible neurological basis for symptoms that challenge people (Leary & Hill, 1996).

What we are learning is that we have a lot to learn from people labeled as autistic. We welcome the emerging voices of people who are speaking, pointing, drawing, writing and typing about their experience. We understand that until recently, we only knew our experiences, that is, as people with significant difficulties communicating and relating to people labeled with autism. We found that when we changed our assumptions about labeled people, we were able to relate better to people with the differences that are labeled "autistic." We now understand, for example, that people may be interested and listening even though they may not look at us. People have feelings and emotions even though we may not see these expressed on their faces. People may have differences in their ability to organize and regulate sensory information and may move in unusual ways. People may have language and not be able to share it. People have competencies that we are not capable of knowing—yet.

Our task now is to continue to explore. We need to break down our biases and old attitudes. We need to open ourselves to new ways of relating to people irrespective of their differences. We need to share our emerging understanding with those who are willing to listen. While we are learning, we will promote effective supports that: build people's self-confidence; do no harm; make two-way communication possible; assist people to accommodate differences in order to learn and participate; and are sensitive to the significant challenges people face. We appreciate the interest, patience and generosity of our best teachers, those labeled with autism. We trust you will enjoy learning from their contributions to this issue of TASH *Connections*.

Anne M. Donnellan, Ph.D. is Associate Provost at the University of San Diego. Martha Leary is a Speech Language Pathologist in Halifax, Nova Scotia, Canada. Comments about this article may be sent by e-mail c/o <pnewton@tash.org>

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TASH: Public Policy in Action

(Left to right) Jim Conroy, Jamie Ruppmann, Donna Szamatowicz, Marge Brown, and Bill Coffelt begin the 2002 NConSD Washington Initiative in the office of Senator Arlen Spector of Pennsylvania.

National Coalition for Self-Determination Goes to Capitol Hill

The National Coalition for Self-Determination (NConSD) held their Second Annual Washington Initiative, June 10-12, 2002. Despite an early summer heat wave, members of the Coalition lugged excellent materials provided by Jim Conroy and the staff of the Center for Outcome Analysis to the Hill for meetings with key Congressional staff.

NConSD continues to urge that policy makers end the institutional and nursing home bias in funding services and supports for people with disabilities. We discussed the positive outcomes for people who have been moved to community settings, and the unfairness of the enormous difference in salaries paid to support staff in community settings versus institutional and congregate placements. The bottom line is that there is a need to reject outdated assumptions that keep community services and supports continually in the position of being considered an "add on" or luxury that receives the last dollar rather than the first.

TASH Governmental Relations Director Jamie Ruppmann provided assistance and support to the NConSD Board and members in planning and executing the 2002 Initiative. In addition to TASH, Jim Ward of ADA Watch and the staff of People for the American Way provided a meeting room and conference call services for the Washington Initiative. For more information about the National Coalition for Self-Determination, contact Bill Coffelt through www.oaksgroup.org.

President's Commission on Excellence in Special Education Update

In a series of marathon "consensus" sessions May 30-31 and June 13 and 14, Commission members completed their report and recommendations. It is expected that the report will be completed and delivered to the President at the beginning of July. Printed copies and a Federal Register notice will be available several weeks later. Both the House and the Senate will be reviewing the Commission recommendations in hearings to be held July 9 and 10.

For more information about these and other issues related to public policy contact Jamie Ruppmann, jruppmann@tash.org

Teach in the Area of Moderate/Severe Disabilities

California State University, Northridge has two federally funded projects in the area of teacher training.

Project SOS: Supporting Our Students helps teachers earn their Level I California Preliminary Credential in Moderate/Severe Disabilities. Project SMART: Support Through Mentoring, Assistance and Resources for Teachers helps teachers with a preliminary credential earn their Professional Level II Credential in California with a MA degree.

Both programs provide financial and mentored support for those interested in working with students who have been labeled with moderate, severe and/or multiple disabilities in inclusive educational settings.

Courses and fieldwork experiences are designed to provide teachers-in-training with the necessary skills and knowledge to facilitate the inclusion of students with severe disabilities in general education settings while providing a meaningful and functional curriculum designed to meet each student's unique needs.

If interested in this program, contact Dr. June Downing at 818-677-5261 or send an e-mail to june.downing@csun.edu

Thank You!

TASH's work is dependent on the financial assistance of our donors and members. We wish to acknowledge the generous donations of the following individuals:

Cynthia Azama

Caren Sax

Don't forget about TASH's lifetime membership option! Lifetime membership entitles you to full international and chapter member benefits for your lifetime, and the cost can be remitted over several monthly payments. If you are interested in becoming a TASH lifetime member, please contact Rose Holsey at 410-828-8274, ext. 100.

Project Coordinator

Institute for Community Inclusion
University of Massachusetts Boston

The incumbent manages federally funded educational improvement, leadership, and personnel preparation projects at the Institute for Community Inclusion (ICI). Duties include coordinating working groups of faculty and staff; building relationships with public high schools; conducting presentations and training; developing a written model of IHE restructuring; managing master's and doctoral degree student affairs; advising doctoral students; participating on dissertation committees; coordinating program evaluation, grant and program development. Qualifications: Ph.D. in education and/or special education or educational administration/leadership. At least 5 years' full-time professional experience in teaching or a combination of teaching and educational administration. Experience educating students with disabilities in inclusive classrooms. Knowledge of issues in urban education, school reform, inclusive education. Familiarity with educational pre-service training practices. Strong interpersonal, writing and oral communication/presentation skills. Ability to travel statewide. Hiring Salary Range: $52,409-$62,892. Normal Starting Salary Range: $52,409-$57,650.

Send resume, cover letter, and names, addresses and telephone numbers of three references to: **UMass Boston, Human Resources, Search 285, 100 Morrissey Blvd., Boston, MA 02125-3393.**

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How Does One Honor the Memory of a True Leader?

And so we must again bid farewell to one of the truest pioneers of self-determination and revolutionary change to ever share our passion and grace our presence. Although many were fortunate to have both professional and personal relationships and enduring memories of Justin Dart, all of us, the entire civil rights community, will be forever touched by his relentless and unwavering support of human rights and the empowerment of people with disabilities.

The TASH community was privileged to have Justin as its 1996 keynote luncheon speaker at the TASH annual conference in New Orleans. It was during his stirring address that Justin challenged each of us to become a part of the "...revolution of empowerment. A revolution that will empower every 21st century American to live his or her God-given potential for self-determination, productivity, and quality of life."

Justin spoke to the thousands of TASH members worldwide and every conference attendee that afternoon when he charged each of us with the responsibility to "...keep the promise of Justice for All." His distinctive voice resonating throughout the ballroom, Justin reminded us that just as he and his family made a commitment to carry the mantle for freedom and self-determination we, too, have the responsibility to strike down "public policy that does not meet the needs of people with disabilities" and "prove beyond any doubt that we have the potential to be fully effective contributors to the economy and to the culture."

Those of us fortunate to have heard Justin's last keynote address to a TASH audience will long remember not only his powerful words, but his challenge to every listener:

"My colleagues, empowerment in America is possible. We have the money, we have the talent, we have the technology. Now do we, as a nation, have the will and the courage to change? How can we possibly overcome the powerful lobbies for the status quo and for retreat? Who will save the dream? Look around this room. The buck stops here. We have accepted, we have chosen responsibility. We are responsible to every person with a disability. Every family with a disability in the world is responsible because the world will follow what we do. We cannot afford to fail. You, who have done so much. We, together have got to do more. We have got to win. Now, where do we start?

We start by getting off of the defense and on to the offense. If enough of us, a critical mass, are willing to pledge our lives, our fortune and our sacred honor, if we are willing to make real sacrifices, if we are willing to go to our personal Valley Forges and to stay there however long it takes, we can prevail. Support TASH absolutely. Don't wait for anyone. You don't need a title or invitation to make history. You can be a revolution of one. Speak out, reach out, mobilize. If you can motivate, if you can activate, if you can educate just a handful of those beautiful Americans who now are spectators in the struggle, we can win."

Although his presence will be missed more than can be expressed in a few words here, the spirit, heart, and soul of Justin Dart and the work to which he tirelessly devoted his life must continue in the daily efforts of each of us. That work must flourish, multiply and replicate.

The July/August issue of TASH *Connections* will feature a tribute to Justin Dart, including highlights from the July 26, 2002 ADA celebration and the memorial service in his honor.

Priscilla Newton, Editor

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"Justin Dart, An Obituary"

June 22, 2002

By Fred Fay and Fred Pelka, written at Justin Dart's request.

Justin Dart, Jr., a leader of the international disability rights movement and a renowned human rights activist, died last night at his home in Washington D.C. Widely recognized as "the father of the Americans with Disabilities Act" and "the godfather of the disability rights movement," Dart had for the past several years struggled with the complications of post-polio syndrome and congestive heart failure. He was seventy-one years old. He is survived by his wife Yoshiko, their extended family of foster children, his many friends and colleagues, and millions of disability and human rights activists all over the world.

Dart was a leader in the disability rights movement for three decades, and an advocate for the rights of women, people of color, and gays and lesbians. The recipient of five presidential appointments and numerous honors, including the Hubert Humphrey Award of the Leadership Conference on Civil Rights, Dart was on the podium on the White House lawn when President George H. Bush signed the ADA into law in July 1990. Dart was also a highly successful entrepreneur, using his personal wealth to further his human rights agenda by generously contributing to organizations, candidates, and individuals, becoming what he called "a little PAC for empowerment."

In 1998 Dart received the Presidential Medal of Freedom, the nation's highest civilian award. "Justin Dart," said President Clinton in 1996, "in his own way has the most

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Honoring the Memory of a True Leader

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Olympian spirit I believe I have ever come across."

Until the end, Dart remained dedicated to his vision of a "revolution of empowerment." This would be, he said, "a revolution that confronts and eliminates obsolete thoughts and systems, that focuses the full power of science and free-enterprise democracy on the systematic empowerment of every person to live his or her God-given potential." Dart never hesitated to emphasize the assistance he received from those working with him, most especially his wife of more than thirty years, Yoshiko Saji. "She is," he often said, "quite simply the most magnificent human being I have ever met."

Time and again Dart stressed that his achievements were only possible with the help of hundreds of activists, colleagues, and friends. "There is nothing I have achieved, and no addiction I have overcome, without the love and support of specific individuals who reached out to empower me.... There is nothing I have accomplished without reaching out to empower others." Dart protested the fact that he and only three other disability activists were on the podium when President Bush signed the ADA, believing that "hundreds of others should have been there as well."

After receiving the Presidential Medal of Freedom, Dart sent out replicas of the award to hundreds of disability rights activists across the country, writing that, "this award belongs to you."

For the complete obituary by Fred Fay and Fred Pelka, go to <www.icanonline.net/>

"I AM WITH YOU. I LOVE YOU. LEAD ON."

Dearly Beloved:

Listen to the heart of this old soldier. As with all of us the time comes when body and mind are battered and weary. But I do not go quietly into the night. I do not give up struggling to be a responsible contributor to the sacred continuum of human life. I do not give up struggling to overcome my weakness, to conform my life - and that part of my life called death - to the great values of the human dream.

Death is not a tragedy. It is not an evil from which we must escape. Death is as natural as birth. Like childbirth, death is often a time of fear and pain, but also of profound beauty, of celebration of the mystery and majesty which is life pushing its horizons toward oneness with the truth of mother universe. The days of dying carry a special responsibility. There is a great potential to communicate values in a uniquely powerful way - the person who dies demonstrating for civil rights.

Let my final actions thunder of love, solidarity, protest - of empowerment.

I adamantly protest the richest culture in the history of the world, a culture which has the obvious potential to create a golden age of science and democracy dedicated to maximizing the quality of life of every person, but which still squanders the majority of its human and physical capital on modern versions of primitive symbols of power and prestige.

I adamantly protest the richest culture in the history of the world which still incarcerates millions of humans with and without disabilities in barbaric institutions, backrooms and worse, windowless cells of oppressive perceptions, for the lack of the most elementary empowerment supports.

I call for solidarity among all who love justice, all who love life, to create a revolution that will empower every single human being to govern his or her life, to govern the society and to be fully productive of life quality for self and for all.

I do so love all the patriots of this and every nation who have fought and sacrificed to bring us to the threshold of this beautiful human dream. I do so love America the beautiful and our wild, creative, beautiful people. I do so love you, my beautiful colleagues in the disability and civil rights movement.

My relationship with Yoshiko Dart includes, but also transcends, love as the word is normally defined. She is my wife, my partner, my mentor, my leader and my inspiration to believe that the human dream can live. She is the greatest human being I ever known.

Yoshiko, beloved colleagues, I am the luckiest man in the world to have been associated with you. Thanks to you, I die free. Thanks to you, I die in the joy of struggle.

Thanks to you, I die in the beautiful belief that the revolution of empowerment will go on.

I love you so much. I'm with you always. Lead on! Lead on!

Justin Dart

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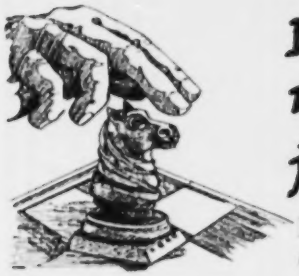

IT'S YOUR MOVE

BY PEYTON GODDARD

[**Editor's note:** Peyton Goddard wrote this essay as an assignment for her college Freshman English class; it is designed as an argument/persuasive essay. It was also presented in a session entitled *"Facilitated Communication: Our Lives, Our Stories,"* at the November 2001 TASH conference in Anaheim, California]

Addressed Audience: Directors of Education
Our Town, U. S. A.

I quest a job and a purposeful life; you tell me that I am stupid. By not accommodating my movement disability, apraxia, the sure bet is that I cannot get an education. Please tilt your present thinking opposing people such as myself to access facilitated communication (FC) by continuing to use the excuse that FC is a fraud.

I am a person who needs touch to move. If the physical resistance to my hand, wrist, forearm, or elbow, which is a necessary accommodation for the success of my purposeful movement, is a strategy I can count on not being supplied, than the hulk of my life is insanity because you, the educator, and I, the student, cannot co-exist in peace. You become the careless oppressor daring to try constantly the ploy of controlling my behavior. I become the oppressed, even though I am neurologically unable to dependably move in complying ways to your exploiting directives. Ill we both become because you become oppressed also by the never successful strategy of control. Looking at climbing this hill we should not be. Your being able to hear what I say is what eventually frees the fullness of a life I gut wrenchingly desire.

The journey I am on is tough. Up in the expanse of my brain I cannot compartment my golden desire to plot my allotted, motor-planned moments of movements successfully. I am verifying that I know intelligence in my somewhat differently operating brain; you presently are verifying by the daffy ways I move that I am an idiot. Therefore, jolly opportunities for learning and living I am not allowed, and wasting I am. Please kill my movement insanity with the quest of your touch, allowing the tilting eagerly of my brain compartment so that my moments turn jolly as I moll plotting golden dependable movement mopping my brain, and mull never the insanity of motor madness again.

Sadly, the main reason that you and I presently never reap peace is that you regulate the policies that ultimately control me. In cases of your inflexibility and understanding not another way of readying people for life, you imprison me. Unfortunately, things will not be peaceful until you and I no longer listen to dangerously inflexible people who are unable to tolerate ambiguity and embrace change. You and I together must joy quest to answer the dream of people appearing dumb by supporting students with apraxia to exhibit their intelligence by implementing the strategy of facilitated communication. You are among the few who have the great opportunity to change the lives of thousands. Therefore, I implore you to teach resistance therapy, the tugging barely method of typing with support.

However, you will golden gut wrenchingly have to protect yourself journeying into territory loitered with land mines that declare you greatly foolish. Others will say FC is a fraud. Gear up to each day answer the questions that will plague you. Reach into your fearless leadership mind, carefully preparing arguments for the oppositions claims-that people like myself should be treated utmost as retarded because we behave retarded, that parents are trying to falsely plot wishful evidence that their children are not dumb, and that tilting ready research supports that people like myself cannot pass messages in scientific studies.

Ordinarily, it is pretty pleasurable to learn radically good-looking news about a person, such as that they are capable of learning and contributing to society. In the past twenty years countless facilitated communicators all over the world have moved to finally access their "voice" through support typing, to leave institutions and live in their communities, to acquire an education including college, to have contributing jobs, and to move to typing independent of touch. Thinking I am that the reasoning of ego driven doubters still whispering or yelling "FC is a fraud" inspite of the documented successful journeys of these people is insane. Kill your gut wrenching plugging of possibilities about what the toll of this great news may hold for you personally and professionally, and open your imagination to realize anything is possible in the golden human soul.

The choice to implement facilitated communication is challenging. As leader, you must rule out the early unscientific data, incorrectly gathered and unjustly reported on Frontline PBS, the toll of which kept me, for one, filled with the insanity of voicelessness, plotting suicide for five additional, unnecessary years. In respected research studies many people have proven beyond any doubt they can message pass.

Embrace as a true leader the infinite opportunities facilitated communication enables and the promise of great luck in this discovery allowed by ignoring old ideas. The cost of believing requires the brave replacement of your illusion data representation of retardation. I count on the overcoming of this longstanding myth early in this millennium.

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IT'S YOUR MOVE

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On your path to implementing FC, you'll hear many opposing your choice. They have long convinced themselves that people such as I deserve no education because I am filled with nothing in my thinking brain. The truth is that pleasurable learning is sought by my brain at all times. All my life I search for opportunities to learn all things hidden in the hulk of readily available, print-rich environments. Never ultimately is the brilliance of the barely ignited brain turned off. Therefore, you'll eagerly look at the ambiguity of my movements, and see a person intelligent, who realized literacy mulling self-sought learning while receiving no real education in school.

Carefully, you'll need to consider the thinking of opposition that calls FC a parental tool freeing their stupid children to look silly never again. Overcoming this argument requires you to understand that millions of parents bet on their kid's myth of retardation. The hill that FC requires of them is mounting the reality that all the years of looking at their kid as dumb is not regainable. Their parenting has been disabled by schools that opposed educating their child's ability to journey to a productive job and the toll of the wasted years they hopingly attempt to regain before they die. The heartaching coping will kill many reasons of cool joy and opportunities for peace in marriage. Furthermore, never caringly would they want to fraud gently plow an ultimate hoax because they could never die in peace. Who would then be left to cover or continue their hoax? Join your leadership plan to embrace ambiguity by realizing what parents want is that their child has a life after they are gone.

Cautiously prepare for the opposition's representation that studies "prove" FC is a fraud. In reviewing scientific, polluted-not studies, I'll think you'll scrutinize carefully so that nothing is incorrectly alluded to that could harm humans. The journey touch-tugging on my arm is very personal. You must be someone ultimately I trust. If opposing you I am, then arriving at valid data is impossible.

You my great face will teach the world through my verified fingers and never can I feel safe if your unethical hang-ups empty my brain. I must type with the power of hurdling no emotions. As leader, you must rule-out the early unscientific data, incorrectly gathered and unjustly reported on *Frontline PBS*, the toll of which kept me, for one, filled with the insanity of voicelessness, plotting suicide for five additional, unnecessary years. In respected research studies many people have proven beyond any doubt they can message pass.

The choice to implement FC is challenging. Bullishly arm your daring with my arguments and create exponential opportunities for those who await. Know that I will be watching. It's your move.

"Larry's personality is shaped not by nice guy behavior but by neurological chaos, so you can't separate good advocacy for self from supportive language interventions."

— Larry Bissonnette, speaking about himself at the May 3, 2002 *"Breaking the Barriers"* meeting to explore people with autism participating in public policy efforts

ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of JASH for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this:

Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year — in addition to an extra full year's worth of journals!

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To learn more about TASH's Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

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"I Have Always Loved These Guys, But Now I Respect Them": A Note to People with the Label of Autism on Personhood and Expression-of-Self

BY SALLY R. YOUNG

Back in the early 1980s I started an expressive arts painting program for a group of 30 adults who attended a day program. None of the people in the program could speak, many had the label of autism, and a large number of them had recently been released from the state hospital system. They "got in" to this particular day program because they did not have the functional skills to sit at a table and sort widgets or do assembly-line tasks in a sheltered workshop.

The support staff there worked in lab coats (is this starting to sound like a mini-institution?), their pockets filled with ever-ready rewards — M&Ms, peanuts, and raisins. Nearly all of the human interaction and all of the participation in activities were governed by the rewards system. When I showed up on the scene with my plans for an expressive arts program, my ideas seemed pretty radical — ideas such as participation by choice, no rewards, no coercing or cajoling, and letting the "people being supported lead the process.

As we were getting ready to begin, I was assigned a direct care staff person to work as my assistant. Ginny had worked in the field several years and, like many of her peers, she needed to have two full time jobs to make ends meet. She worked both at the day program and in one of the group homes where the people supported in the day program lived. Working for two different agencies meant she had been well-trained in the behavioral techniques of the day. Although these techniques were the unquestioned method of interaction and training, I was thankful that she seemed open to something different.

Gaining Personhood

The art program got underway and before long people were furiously and enthusiastically painting. They began to reach for colors that sat on the other side of the table, they began to indicate when they were ready for a new paper, they began to sit at a table longer than they ever had before, they began to display greater attentiveness, and they began to work very hard at their art.

A few days into the program, Ginny began telling me how exciting it was for her to see people painting. She explained to me that she thought she knew them so well - what they would and wouldn't do, what they could and couldn't do. Now suddenly she was seeing them doing new things, acting in new ways, and being truly engaged in an activity. I began to wonder if something was changing in Ginny and one day she confirmed my suspicion. As she was talking about how differently everyone acted in the art room, she said to me, "I have always loved these guys, but now I respect them." Ginny's mind was shifting from seeing them as clients to seeing them as artists. Giving someone love is one thing, but giving them respect is quite another altogether.

Being part of the art program was turning Ginny around and, at the same time, her words were turning me around. Expressive arts had been a powerful force in my personal life and until that time I had been mainly thinking that people who do not speak must need some kind of expressive outlet. I had not thought about the impact the art program could have on the staff.

Autism and Expression-of-Self

Autism is, almost by definition, a disorder of expressive language. We are learning from you, especially those of you who use facilitated communication (FC), that you have receptive language that far surpasses your expressive language.

We know also from Anne Donnellan and Martha Leary that sensory and movement differences can potentially interfere with your body language. When you do not have accurate body language and you cannot speak, you are almost certainly at risk for being misinterpreted and misunderstood (Radisch cited in Young, 2000).

Many of you have told us about your predicament of not being able to act and behave in ways that accurately reflect your desires, thoughts, feelings, and inner states. For example, Sandra Radisch has said that she can be crying on the inside but her eyes are dry (Young, 2000). Eugene Marcus has described a wooden Pinocchio with the soft beating heart of a real boy (Marcus, 1998). Donna Williams (1995) said she had a self that had been buried alive, and Sue Rubin (1998) has likened her face to concrete, saying it never shows sadness or anger. In each of these cases the capacity to reveal or express the self is somehow thwarted.

Our perceptions and judgments of others are based on an assumption that there is congruence between inner state and outer behavior (Jacobson, Mulick et al., 1994). When this congruence is lacking, all forms of self-expression are subject to misinterpretation and all traits that are inferred from outer behavior, such as intelligence or emotion, can appear to be absent (Donnellan and Leary, 1995).

In today's society, the personhood of people with disabilities is often at risk. This risk can be even greater for those of you with the label of autism since your sensory and movement differences often prevent you from being able to accurately express yourself in daily life. Through the expressive arts, you can explore, develop, and articulate your own point of view.

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"I Have Always Loved These Guys, But Now I Respect Them"

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Speech, body language, and eye contact are the typical avenues for our everyday expression-of-self. Being stripped of some or all of these everyday forms of expression can make you seem fundamentally different and this potentially can pose a threat to your perceived humanness or personhood.

Threatened Personhood

For most of us, it is through the everyday avenues of self-expression that we build relationships and maintain our membership in the human community. For you, it is these very avenues of self-expression that have developed differently. For example, if you have a label of autism you might move in a rigid or mechanical way, avoid human touch, avoid eye contact, have a flat affect, and/or speak in rote, stilted phrases. With these kinds of movement differences it appears as if your lack of emotional expression and human connection is of your own choosing. Consequently, it appears as if you are not interested in other people and that you are intentionally breaking the human social contract.

In our society, humanness, or personhood, is attributed to those who keep the social contract for relatedness and show or tell us, more or less, what they are thinking and feeling inside. Many of you have told us that you know your personhood has been jeopardized. For example, Eugene Marcus noted the connection between having an expressive language and personhood when he wrote, "FC is a way I got a shot at being a real person" (Marcus, 1998). Rob Cutler (2000) made a similar connection when writing about his life before FC saying, "We were perceived as unworkable, unhumans of society."

Expressive Arts

Every human being has an individual point of view. This point of view is carved and polished by the choices we make in everyday life and is continuously challenged and confirmed by interacting with other people and the environment. In all of us, there is an urge that pushes us towards developing and refining our own point of view. Those among us whose whole lives are devoted to this task are the ones we call artists.

The expressive arts are an excellent way to explore, develop, and articulate your own point of view. As Donna Williams has said, she gained her voice and her sense of selfhood through her fingers with a pencil, paintbrush, piano, and typewriter (Williams, 1995).

The creative process is one of change and of finding a new order for the inner or subjective life. When new life is waiting to come forth we often become trapped in rigid patterns of thought and feeling. As Van Gogh noted, when we have not found the path of expression, we feel as though we are trapped in a horrible cage. The expressive arts can give all people, but especially those living with limited life choices, a new sense of freedom and control.

The principles of the expressive arts can be applied to any artistic medium and people with autism have found great success in programs using poetry, journal and life story writing, painting, drawing, music, drama, and dance. The arts are an expressive language and its vocabulary is open to all.

Using the language of art can be a catalyst for change and expressive arts therapists often say that one form of expression flows into another (McNiff, 1981). We have seen evidence of this effect in the people who have spontaneously started to speak or move differently after extended use of FC.

Conclusion

In today's society, the personhood of people with disabilities is often at risk. This risk can be even greater for those of you with the label of autism since your sensory and movement differences often prevent you from being able to accurately express yourself in daily life. Through the expressive arts, you can explore, develop, and articulate your own point of view. At the same time, you can impact positively the perceptions that others may hold of you.

As "poet-in-waiting" Sandra Radisch has noted, there is a connection between her poetry and the degree of personhood that might be attributed to her. She writes, "I want and will make more poetry. In the future I will place more value on my art. That may be my claim to my humanity" (Young, 2000).

Watching people paint changed the way Ginny saw them. Your creative process, your words, and your artworks are the most powerful forces at hand for turning minds around and for gaining the respect and personhood that you deserve. You deserve love, yes, and you also deserve respect. Keep painting your worlds, writing your stories, and singing your songs. Ask for opportunities to do art and express your inner realities and be ready when the opportunity comes your way.

Birger Sellin (1995) and I are calling to you - he, much more eloquently than I.

He writes:

now I am going to write a song about the joy of speaking
a song for mute autistics to sing in institutions and madhouses
I am singing the song from deep down in hell
I am calling out to all the silent people in this world
make this song your song
thaw out the icy walls
make sure you aren't thrown out
we will be a new generation of mute people
a whole crowd of us singing new songs
songs such as speaking people have never heard
of all the poets I don't know of one who was mute
so we will be the first
and people won't be able to shut their ears to our singing
I'm writing for my silent sisters for my silent brothers
we want people to hear us and give us somewhere
we can live among all of you
live a life in this society

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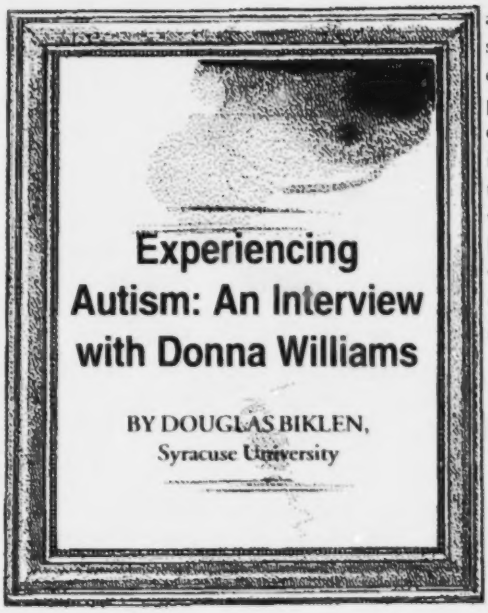

Experiencing Autism: An Interview with Donna Williams

BY DOUGLAS BIKLEN,
Syracuse University

Donna Williams is well known for her best selling books, "Nobody Nowhere" and "Somebody Somewhere." In addition to these works, she has also produced a number of other books, including several that include guidance for teachers, parents, and others who want to interact with people with autism.

Conducted via e-mail, this interview focuses especially on issues of communication, competence, and autism. When I asked Donna to write a piece for TASH, Donna suggested we do it in the form of an interview. So I sent her a series of questions and she responded a day later. For further information about her publications and other resources, you can visit Donna Williams' website: www.donnawilliams.net.

Biklen: As we begin this interview, I want to emphasize that I am asking for your reactions to a range of issues, but I don't presume to put you in the position of speaking for all people with autism or even to say, "this is how autism works." Rather, I am just hoping you might share your thoughts, based on your own experiences and observations.

Okay, on to the interview. In the introduction to your book Autism Inside Out, you wrote about how people struggle with autism: "it is not everyone who is a good mountain climber but that with the right coaching, everyone is capable of taking a few steps more than they might if not challenged nor expected to do so" (1996, p. vii). This raises the question: what form does good coaching take? I know that's a terribly broad question, but I wonder what a few examples would look like.

Williams: Coaching. I don't like to think about coaching so much as modeling and behavioral dialogue. Also people often confuse an information processing problem with a learning problem.

Ok... so modeling. Here's an example from Nobody Nowhere (Williams, 1989). When I was eleven, I had a lot of things I needed help with but my social-emotional developmental level was very backward, which meant I could sing songs and jingles, use stored sentences, later do observational monologues, but couldn't initiate interpersonal communication on a personal level and, especially, could not answer on a personal level when someone else initiated the dialogue. This meant I was very communicatively stuck.

My solution was to chatter to my feet, but I was unable to turn up the volume for the purpose of the listener, unable to disclose who the intended listener was, unable to define who I was speaking about nor be specific in disclosing the topic itself. To have done any of these things would have triggered involuntary self-protection mechanisms which would have severed the line of communication entirely, leaving me nowhere.

In other words I looked like a disturbed child with dysfunctional language (who) mutter(ed) to herself unintelligibly. A teacher who had tried to get me to communicate found it only triggered my cut off. He learned instead to get out of my space and into his own. He learned not to ask questions, but to say open-ended statements out loud to himself. He didn't sit opposite me, but sat alongside me with the distinct feel of being in his own space as he talked to himself. His indirectly confrontational approach used triggering on a preconscious level to free up my dialogue WITH MYSELF before him. To have relied on an expectation of conscious accessing would have got him nowhere, for as soon as I myself had conscious awareness, the connection with functional language self-protectively disconnected me. What this example shows is that modeling and behavioral dialogue worked much better for me than coaching. The coaching, to someone with Exposure Anxiety, merely highlighted for my acutely self-protective mechanisms which bridges the invasion would take and triggered the burning and progressive avoidance of those bridges.

In terms of learning difficulties versus processing difficulties, the example of the supermarket helps. Because of delayed information processing, I had no conscious access to the huge accumulation of knowledge I'd gathered peripherally so I had no awareness I had mathematical ability. Consciously I could not add or subtract from twenty at the age of nineteen. Yet, when a difficult mathematical equation was thrown at someone else, it triggered the preconscious awareness and an answer would come up, without any conscious idea what it was associated with. When I was taught remedial mathematics, giving me a conscious awareness of math at the usual level of late elementary school, I still couldn't work out the simplest of change most of the time. This was not that I hadn't learned, nor that the knowledge didn't float around in their somewhere. It was generally that my processing of the mathematics problem was far behind the activity of getting the change, so it appeared I had no idea.

Other activities are like a sticky switch. Facing one direction in one room I won't access the information. Sitting in another room facing a different direction and somehow the link connects.

Then there's the issue of Exposure Anxiety causing shutdowns in spite of tremendous learning (I write about this in Autism, An Inside Out Approach but also in my upcoming book, Exposure Anxiety: The Invisible Cage). But also, there's the left brain way of learning -- which is conscious and verbal and using intellect, and the right brain way -- which is preconscious, may connect through

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typing but not speaking, and relies on mapped sense of pattern, felt theme and the feel of an object, person, situation rather than interpretation based concepts. Some people are right-brain dominant and assumed unintelligent because their intelligence takes a different form and expression to left-brain dominant people. The "split" brain phenomenon occurs when someone uses each side, though basically independently of each other.

Just because someone doesn't use their processing in an integrated way doesn't mean they are not intelligent, but their way of expressing that intelligence may require different techniques, different 'keys' of triggering the information, and the language itself may be quite individual in some cases. So, as I described in Autism And Sensing, in sensing-based language, 'degoitz' is the word for the pulling back feeling I now call Exposure Anxiety. It evolved into 'lemons' and 'causing me lemons,' but this was describing the feeling caused by exposure.

The word for cat was 'broook' (the sound made by the cat) and 'fooosh' (the low, almost inaudible sound made by patting). Valid communication, if you understand sensing-based language and the sound coming from the entity known to most as 'cat' or the sound produced when patting such an entity. So I think sometimes the definition of language is also quite narrow and there is an assumption that if it's not 'interpretive, left brain' language (then) it's not valid or comprehensible and I think that's lazy and unimaginative to think that way.

Biklen: When Asperger wrote his first article about autism in 1944, he argued that whereas "Human beings normally live in constant interaction with their environment, and react to it continually... 'autists' have severely disturbed and considerably limited interaction" (Asperger, 1991, p. 38; this is a translation of Asperger's 1944 article). This raises several questions in my mind: Is interaction disturbed, or is it better to say different? If it is different, is it limited or is it rich in ways that the outside observer cannot know?

Williams: I think that most people lose the wide variation of language systems they start with. They have so-called 'non-verbal' sounds and movements which express all kinds of emotional and physical experiences, many of which have no words in interpretive language of the left-brain mind-self. Many people with autism still have this but it's generally discouraged and very rarely do people seek to understand it as comprehensible 'language of behavior.' Especially when it's indirectly confrontational and self-in-relation-to-self, most people assume it couldn't possibly be language unless its self-in-relation-to-other and directed in a directly confrontational way.

I think words like 'disturbed and limited' depends on the observer. My best interaction is to bounce along enjoying the experiences I encounter, making of them what I will (mostly with little or no cognitive left-brain interpretation in the moment), allowing my right-brain sounds and movements to roll out unsuppressed and unashamed, and to feel uninhibited by others with me because their ability to interact with the world in a self-owning and sensory based self-in-relation-to-self way is still intact. We still would perceive each other but in our own world, and peripherally, yet none the less relevant than had we done so in a directly-confrontational way.

Now for me, there are many times I watch people bland of involuntary sounds and movements of their (suppressed) right-brain self, relying only on interpretive left-brain, mind-driven blah, blah in which the experience of each other is a mental, kind of meta-world and I feel sorry for them, waiting for them to have a buzz. It's only because left-brain non-auties (and predominantly left-brain Aspie's) are the majority in verbal society that I try, against much instinct at times, to stay as left-brain and cerebral as possible while in their company. That's because conscious thinking and speaking with awareness doesn't come naturally to me. I don't relax with it. It feels 'plod', 'plod' a lot of the time (but typing is different). I can do it (like speaking a foreign language), but complex verbal communication feels like lots of rust, like wading through mud. I'm naturally predominantly right-brain, so I love to buzz and get into patterns, whether I can speak or not.

> Most non-autistic professionals assume we all work best when we intellectually learn, prove that intellectual knowledge and thereby -- and only then -- 'earn' the right to 'do.' This sets a lot of people with autism up for failure if they learn only through doing.

I'm good at being (that way). But most of the world isn't like that, so to be what comes most naturally to me would mean social exclusion from a large part of society. So I do feel experiential reality for predominantly left-brain people is all a bit reduced for them by virtue of consciousness and reliance on a verbal world in which interpretive interaction is superior for them to a sensing-based one.

It's only that they are the majority and the consequences (related to exclusion) that I try, against much instinct at times, is to stay as left-brain and cerebral as possible while in their company. But I still love some of these foreigners.

Biklen: Related to this, if a parent or teacher observes a young child with autism seemingly not reacting in conventional ways to communicate with other people -- for example if the child is rocking and not looking at the person looking at him or her, or if the child runs away from the person who tries to shake his or her hand and to converse -- what kinds of strategies can teachers and parents use to help the child feel comfortable and to engage?

Williams: The person is force fed with self-in-relation-to-other directly confrontational unasked for sensed 'invasion.' What is missing is 'want' and getting want when force fed with more attention and clinging than one can socially-emotionally handle, is impossible. I don't say leave the person alone, but do get realistic and honest. Praise can be inhibiting, an allergen, for some people.

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Forced inclusion can feel like imprisonment and trigger social claustrophobia. So get real. Don't put non-autistic projections onto what may be a very different social-emotional developmental reality. Think about when you are being pursued by the person with autism. If it's when you are busy, when you are tired, when you aren't looking, waiting, wanting, then listen to what that tells you. If you want to promote something, be aloof, low key, self-owning, self-in-relation-to-self, fly on the wall. Keep interaction in small doses, be strategically indirectly confrontational, play hard to get and always leave the activity with the person wanting more. If yes self-protectively brings a retaliative no and no brings yes, then use no to trigger yes and the invasive social joining of yes to inhibit unwanted behaviors. Number one, dare to question the experts and don't be conned that robotic compliance is success when it is used self-protectively to get out of the excruciating self-exposure of doing from want and as oneself (which is not the same as doing as you).

Biklen: Some children do not speak (or seem not to speak), although I remember once that you told me that many children who are said to be non-verbal in fact do speak some, and that this could be recognized by paying careful attention to the sounds they make. How should the teacher approach conversing with the child? I assume, from knowing you and reading your work, that this is not a moment to presume that the child lacks the ability to think in complex ways.

Williams: Absolutely. If someone has severe social-emotional developmental retardation, this says nothing of cognitive capacity. Someone can find social connection excruciating and be triggered into terrible social claustrophobia, compelled, involuntarily, to burn the bridge to this 'invasion' through the inhibition of speech. This doesn't mean they don't continue to process information. Even those who also have information processing problems (and not all do) still have delayed information processing, though triggering techniques including multiple choice, and going for incorrect answers to trigger a correction, may be needed for them to incidentally discover their own unknown knowing.

I think that if you are going to pay close attention in mapping the self-directed expression of kids with autism, you would have to be discreet and indirectly confrontational about it. (Otherwise) through this 'putting on the floodlights' effect you'd end up provoking them into pulling away from communicating even from themselves to themselves.

I think the best teachers are those who give up trying to get speech, and sing and rhyme and chatter and write notes and type to themselves in small play-hard-to-get self-directed little doses -- essentially flaunting their own self communication while providing within the environment the opportunity to accumulate written vocabulary labeled on every experiential concept in the environment; cheeks labeled as cheeks, cup labeled as cup, car labeled as car...you get it. Some people can dare to read their typing (communicating via an object and not directly self-in-relation-to-other), but can't communicate verbally directly to someone else. So non-invasively, model what you expect might work.

Biklen: In Autism- An Inside-Out Approach, you wrote about how, as a young child, you 'didn't understand or want or feel safe with the emotions that are meant to drive the interest, need or want to communicate' (1996, p. 2). You went on to say that you were 'perceptually disconnected from' your 'body and face and voice.' Add to this problem, you found your processing for meaning 'was slow, out of context and incomplete' (p. 2). Not surprisingly, under such conditions, you said you had a tendency to ignore or to escape the interaction. I have observed students with autism in inclusive classrooms, and it seems that their performance varies tremendously depending on the moment and situation. So context appears to matter a great deal. Are there a few key rules about how to create the supportive context?

Williams: Keep it directed at the object/issue and off the person. Keep it in small doses, leave them wanting. Be self owning, be there for you, not for them, take the heat off. Provide an indirectly confrontational media of communication or social connection. Get rid of the overhead lighting, especially the fragmenting effect of fluorescent lights. Cut down visual busyness of environment, contain displays in clear, boundaried areas. Sort out overwhelming or invasive acoustic experiences so people can relax less distracted. Slow your speech, use gestural signing as though to yourself, keep communication visual and concrete through objects if involving contrastive information. Especially, address possible nutritional, digestive, immune system, toxicity issues which can severely interfere both in terms of information processing delay, sensory perceptual fragmentation and fluctuation, sensory heightening and acute anxiety (i.e., dairy/gluten intolerance, milk or wheat allergy, salicylate intolerance, sugar and Candida issues, MSG, aspartame, chocolate/caffeine sensitivity, immune deficiency, vitamin-mineral deficiencies etc.).

Biklen: You have written that at the age of 10, meaning started to be more accessible to you, 'though generally delayed' (p. 2). Yet you say you found yourself picking up 'fragments of literal meaning' (p. 2). Are there ways that parents, teachers and peers can make complex ideas available in ways that they might be accessed more easily, and ways of enabling the child with autism to communicate complex content?

Williams: Temple (i.e., Temple Grandin; see Grandin & Scariano, 1986 and Grandin, 1995) thinks in pictures and this is maybe more common for people with Aspergers who are predominantly left-brain. Many people with autism who are predominantly right-brain may be unable to bring pictures or concepts to incoming words, so these words fall 'meaning deaf' on them within the moment or they rely on the 'feel' of the dialogue or general 'theme.' So gestural signing and speaking via objects brings the experience to the words as their experiential meaning is played out and observable. For me this is absolutely essential. But the labeling of all objects with the typed word form helps to link the words directly to the

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sensory/kinesthetic experience. I could not get this from reading. I could understand any words directly on the objects referred to but not read books with interpretation in the moment (scan reading, however, can mean huge volumes are taken in preconsciously and processed outside of conscious awareness). So it is important to build up this repertoire.

Fortunately, I found a picture sentence dictionary when I was nine and I then translated the pictures into sensing-based gestural signing which linked the written with the auditory, the auditory with the visual, and the visual with the kinesthetic -- one very long route to build receptive language, and one that could have been made much easier through gestural signing and labeling.

Biklen: Of course, many people with autism have also mentioned being besieged by anxiety and stress, even to the point of becoming frozen against action, or to the point of feeling compelled into obsessive actions, including familiar routines. Would you talk about stress, anxiety and communication?

Williams: Exposure Anxiety is like a burglar alarm that calls up the internal prison warden. The prison warden slams the bars on the invisible cage, pulling the self back in and triggering involuntary avoidance, diversion, retaliation responses to warn off the invader which had set off the alarm. The self is still in there, but to access it the invaded has to outfox the warden (Exposure Anxiety) and this can only be done through an indirectly confrontational approach. Essentially, this trips no burglar alarm.

I communicated a lot through self-abuse because my own self-protection mechanisms blocked me from using, let alone sometimes even holding, a thought which would lead to a communication which would help me. I had to fill my mouth with ink from a broken pen for six years to provoke being ordered out because I could rarely dare to ask or show the need to get out of the classroom. For years I was compelled to slam the door in people's faces when I'd opened the door to greet them, spouting 'Hiya woman, how's your hormones' -- none of which was wanted or intended. I lunged forward and bit on the arm someone I was asked to meet and to give a congratulatory kiss on the cheek for his upcoming wedding. Feelings of closeness or attachment triggered shredding, slamming my head in my desk. Compliments compelled me to throw chairs, punch myself and drag my fingernails down my face. Attempts to communicate provoked verbal lunges into commercials, jingles and stored lines to simultaneously reassure me of the safety of distance, leaving me looking disturbed. These things are still there, but 80% of the volume of these reactions is turned down through dietary intervention which addressed nutrient deficiencies, dairy/gluten intolerance, milk allergy, salicylate intolerance, an inability to detox properly and an immune deficiency.

Biklen: Recently, from reading autobiographical accounts, I have become aware of how some people with autism actively work to figure out ways of participating in social, communicative situations. Some individuals talk about how they ask friends or paid assistants to help them focus on a particular question that might have been asked, or help them interrupt particular stereotypies so they can respond. Should schools and supportive trainers or agencies be helping people with autism to train aides to give such support where it is needed?

Williams: I think that the person with autism has to be asked whether they want the help. If it is given without being asked for, it is Exposure Anxiety which will open the door and which further imprisons the person with autism. I am very okay with asking someone to preempt or draw attention to an undesired defense response and this can inhibit the response, but if the attempt to suppress the defensive response is uninitiated by the self, then attempts to suppress it will often escalate the behavior.

I do think that support people have to be aware that avoidance, diversion and retaliation responses and communications may be unwanted and unintended, but that the person is in there, too. So do not throw out the genuine, wanted, communication as well. I'd probably address Exposure Anxiety responses with, 'okay, that's what Donna's prison warden wants to distract us with, it can speak in a moment, unless it would like to talk sensibly and tell us how we can help it to give Donna a chance to communicate.' I think it's essential that aides be aware of Exposure Anxiety, that it is not the self (and the self may have sided with it or be terrified of it) and what an indirectly confrontational approach requires.

Biklen: In Asperger's 1944 article, he described several of his students, including one named Fritz who rarely answered questions directly. People usually had to ask Fritz questions many times before he might answer. Sometimes his answers were very brief and indeed 'it was sheer luck if he reacted at all!' Instead of answering, he often began stereotypies. Asperger noted that even when it was clear that Fritz knew the answer to something, 'He deliberately repeated wrongly many of the sentences' (p. 44). His performance was quite uneven in test situations. For example, assessed for his perception of similarities and differences, sometimes he gave a correct answer and often not: 'for the item tree and bush, he just said, "There is a difference.' For fly and butterfly, he said, "Because he has a different name,' 'Because the butterfly is snowed, snowed with snow;' ask about the colour, he said, 'Because he is red and blue, and the fly is brown and black.' For the item wood and glass, he answered, 'Because the glass is more glassy and the wood is more woody.' For cow and calf, he replied, 'lammerlammer-lammer...'. To the question 'Which is the bigger one?' he said, 'The cow I would like to have the pen now.' (P. 45).

Asperger believed that students with autism 'have difficulty in retrieving their knowledge, which is revealed often only by chance.' In other words, the problem was one of performance to outsider's expectations and not indicative of a global inability to think in complex ways. I wonder if you could comment on Asperger's analysis.

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Williams: I think that I began to develop left-brain thinking quite late and receptive language wasn't really on line 'til about nine. So for me, I'm not an Aspie, nor an Autie but an Autie-Aspie, my foundations being Autie but extending eventually, albeit unintegrated, into the Aspie realm. So commenting on Asperger Syndrome is difficult for me, maybe. I can say that his comments for me about retrieving knowledge often only by chance is definitely true of my spoken responses, but much less so of my typed ones. The reason is probably the typed responses come from a different part of the brain, far less triggering of consciousness for me than speaking. Also, speaking is far more directly confrontational (typing is via an object), so more likely to trigger avoidance, diversion, retaliation (disownership no=yes/yes=no) responses.

Biklen: As you know, Kanner published an article a year before Asperger (Kanner, 1943, [see reprint]1988) where he, too, described autism. Three decades later, he declared that he could not have anticipated which students would end up leading the most independent or dependent lives, which would end up employed, and so forth. Yet today, there is a common belief that if children have not demonstrated pretty good communication and social performance by about the age of 12, the prognosis for future performance is not so good. I'm not convinced of this, especially since I have recently observed two men in their late 30s who are now learning to use speech more effectively than they had. Also, I have observed a number of students who became communicative through typing and have become far more independent in their lives, after the ages of 11 and even 13. I wonder if you could comment on the issue of predicting performance, including independence and participation in social interaction.

Williams: I think there are some early speakers whose Exposure Anxiety prohibits their verbal development from extremely obscure, difficult to comprehend, seemingly 'dysfunctional' language (to neurotypicals, that is), and those who don't speak 'til adulthood and either are verbally purely pragmatic, unable to dare the use of interpersonal speech, or fluent and interpersonal but only via an indirectly confrontational media, such as typing or typed communication. Some people may, through such an indirectly confrontational media, desensitize to the inhibition caused by Exposure Anxiety, progressively daring more directly confrontational communication where they can.

I was able in my '20s to communicate on academia, but had little ability to dare non-stored interpersonal communication of a personally exposing nature (which sent me into 'Donna-speak'). I wrote 250 pages of Nobody Nowhere in four weeks, understanding and preempting none of it 'til it emerged before me on the page, as if it was let out rather than deliberately typed. Not all typists are like this, but some are. To think and type would have been painstakingly slow and far more self-protective and dry than the expressive and personal self which emerged. Once exposed before self, I could answer people about it, but basically only via typed responses which I read during interviews and later used as 'lectures.'

After years of this I was able to stray from my typed words -- like sneaking in my free-speech in between the accepted safety of the indirectly-confrontational communication. Progressively, over years, I now speak rather than read my entire lectures, simply using point form notes. It was a tough road. But now, still, so many areas of communication are yet very blocked because I had little social practice outside of academia or the topic of 'autism.' I certainly think that there is opportunity to market one's non-verbal skills if an available pigeon hole doesn't fit, and I think that typed communication should be accepted as valid and equal for those severely challenged by Exposure Anxiety within Autism or Asperger Syndrome.

Biklen: Speaking of another of his subjects, Asperger describes a child named Harro who he says would make up elaborate, fantastical stories: 'his confabulations becoming ever more strange and incoherent' (p. 51). This reminds me of some of the early typing of people who used facilitated communication. I recall one student who told of having hit a teaching assistant when, in fact, he had not hit the person at all (Biklen, Saha, and Kliewer, 1997, p. 64). I wonder what your thoughts are about such communication.

Williams: I think people on the spectrum are all different. Some are capable of making things up (a left-brain ability), some are not (those predominantly right-brain would find even conceiving of something beyond what actually IS quite difficult or impossible). It wouldn't occur to me someone could make something up. I have been told the most incredulous things which I cannot conceive of as impossible.

I'm happy to believe some people on the spectrum can be good self-entertainers. I believe others are good at storing lines or dynamics of previous situations and combining this regurgitation in a way that sounds 'confusing' or 'a lie.' I think there are others who can speak in feel or theme, but are taken literally, sounding like a 'lie.'

For example, the student you mention may have meant that in his own world he 'hit out' at his assistant, not meaning this existed in the observable world. I certainly struck myself when addressed by name to show I had felt struck by the use of my name. I could easily envision explaining this as having been hit so showing others what they had done. So there is no one way to view such communication. Some people, with or without an autism-spectrum condition lie, some with or without such a condition use easily misinterpreted communications they don't seek to clarify.

Biklen: Asperger suggests that teaching and also assessing students with autism requires particular sensitivity and openness to flexible strategies, where the teacher or assessment specialist attempts to discover a child's 'special interests,' experiments with multiple ways of presenting material and posing questions or dialogue. He notes, 'we always let the children produce something spontaneously...' (P. 53). This resonates with me but would seem to fly in the face of the currently popular

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(at least in the U.S.), highly structured, behavioral teaching methods. How do you approach teaching and assessment?

Williams: Highly structured behavioral teaching methods are good at proving that some people can be compliant. If the persons don't then take the ability on for themselves without prompt(s), then they have not made the action 'theirs.' Teenagers, to whom a phase of acute Exposure Anxiety generally comes naturally, do not draw on that with which they are made to comply, often preferring to go without or choosing a very long road to do things 'their way,' so valued because it is connected inside and 'theirs.' The same understanding is not applied to people with autism because it is assumed that if they demonstrate little cognitive self-awareness, then sense of self is not present. This is ignoring that in the absence of conscious left-brain cognitive self awareness, there is no intangible 'felt' self. It is this same felt self the teenager defends against the sudden perceived invasion of the world which expects him or her to move into a new developmental phase for which the teenager is not socially-emotionally ready. It's generally understood that if you want a teenager to do something, you can often get them to do it as though for themselves using reverse psychology or playing hard to get. Yet, it is still assumed that the same Exposure Anxiety in children with autism will respond 'appropriately' to 'praise/inclusion' as reinforcing and 'being ignored/excluded' as inhibitory even though this can have quite opposite effects to the expected within self-protective teenagers.

I think we have to be clear who and what we are assessing. If we use a directly confrontational approach, relying on conscious accessing such as directly confrontational questioning addressed to the person rather than via paper, with someone with severe exposure anxiety, we have a test designed to 'least fit' their condition so it will be successful only in showing how disabled their condition, triggering avoidance, diversion, and retaliation responses too easily taken for everything from stupidity to madness. We may alternatively bring out how robotically compliant their responses can be, yet largely detached from their own felt responses. If, on the other hand, we use an indirectly confrontational approach relying on preconscious triggering such as an open-ended statement, multiple choice or questions left on the page rather than directed straight to the person, with the social 'floodlights' turned down as we allow them their own uninvaded space to answer using an indirectly confrontational media such as typing or pointing (which are via objects), then we increase the chances of getting an intelligible, less self-protective response.

I also think that not everyone works best relying directly on mind. Some people work best communicating via objects to ground their communication. Without these tools, some people's communication falls deaf on their own ears. Some people need to use physical involvement with the topic, able to use kinaesthetic sense and not just the visual and auditory, because they can't hold much in conscious awareness without it all floating off, fragmented (for me it's like confetti in there a lot of the time).

Some people can't hold contrasts within a single comparable context, so they need the two set up physically before them, able to watch the two contrasting 'movies' play out within one held context so they can make informed choices, not guesses, in which each time a new piece of information is moved 'til the last one disappears as it moves into preconsciousness.

People with high anxiety need to know they are free to go in order to feel safe to stay.

So my ideal atmosphere is one in which the student is not expected or assumed to rely on left-brain processing. It is one where it is okay to explore maths, literacy, science through pattern without needing to draw conclusions. It is one where the teacher models and inspires through his/her own interest in the work rather than teaches. It is one where the interaction is indirectly confrontational, self-owned and self-in-relation-to-self so it doesn't trigger Exposure Anxiety. It is one where the use of different sensory systems and the peripheral use of vision or hearing is accepted as an adaptation to best map the feel of the experience.

The ideal atmosphere is one which relies on exploring concepts through movement and through the senses for one's own benefit and not as a matter of eagerly awaited proof. Some people learn through doing. Some are happy to get used to doing and never feel the need to 'realize' the usefulness of the doing they enjoy. Most non-autistic professionals assume we all work best when we intellectually learn, prove that intellectual knowledge and thereby and only then, 'earn' the right to 'do'. This sets a lot of people with autism up for failure if they learn only through doing.

Biklen: About a year and a half ago, several Italian researchers (Bara, Bucciarelli,& Colle,2001) published an article in the journal, Brain and Language, in which they challenge the notion of 'theory of mind.' This is the theory (Baron-Cohen, 1996) that holds that people with autism tend to have great difficulty recognizing that other people may have different points of view than themselves. The typical test of it is done by showing the person with autism and a friend some candies in a tube, then with the person with autism viewing the action, but while the friend is out of the room, the experimenter moves the candies to another location. The experimenter then asks the person with autism where the friend will likely look for the candies.

Inability to answer this question correctly (i.e., 'in the box') is said to reflect a lack of 'theory of mind.' I know from our previous conversations that you are critical of the 'theory of mind' theory, so my question is not: what do you think about theory of mind? Rather, Bara and colleagues posit that difficulties with attention shifting explain much of what has previously been interpreted as a lack of 'theory of mind' attributed to people with autism. I'm wondering how you think about the importance of attention shifting difficulties in relation to autism?

Williams: I think the attention shifting thing is what I call 'all self/no other' and 'all other/no self.' Some people are all self/no other,

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because that's their social-emotional orientation. Most, however, are swinging between all self/no other in which they are stuck in a mono state, unable to track the two pieces of information simultaneously, and that of all other/no self. All self/no other means apparent inability to keep track of 'other.' But all other/no self is about merging with 'other' in order to know it 'as it.' It's like merging with the feel/form of an object, except some people get lost in the patterns of other people, in mapping the patterns and when they do they can't find what they think or feel because they are not on the 'self' track at that time. This doesn't mean that they don't accumulate huge mapped patterns about other, nor that some people may be able to play out in their own world what self-in-relation-to-other might be like (because in one's own world there isn't always the same competition for information processing as dealing with what's coming in spontaneously).

I have trouble doing simultaneous self and other in my head or following dialogue that expects me to hold such a scenario, but I can play it out through objects and keep up when it's tangible and observable and I'm able to hold the two concepts simultaneously. Everyone is different. I think the stereotypes are a pain.

Biklen: In your book, Autism- An Inside-Out Approach, you write, 'I may have a sense of humor and I sometimes even realize someone else is being cheeky or silly, but jokes to someone like me is like moving the furniture on a blind person. I move in a literal world and jokes are a chaos that my processing is generally too inefficient to see until I trip over them. Jokes require processing at a level beyond the literal ... for significance' (p. 152). Clearly this is quite different than Asperger's outsider perspective where he says, with autistic children there 'is the absence of a sense of humor.' Asperger was not reticent on this point; he concluded that 'autistic children are rarely relaxed and carefree and never achieve that particular wisdom and deep intuitive human understanding that underlie genuine humor' (p. 82.) I find this rather odd since a number of people I know who have the classification of autistic do indeed have a rich sense of humor. I wonder if you could comment.

Williams: There's a big difference between receptive and expressive humor. Receptive humor involves keeping up with the processing of incoming information within the moment from the sensory to the literal to the significant in terms of levels. Jokes require all of these, consciously. Yet on an intuitive, non-interpretive level, I might have the feel someone is laughing inside of them and I'll pick up on that feeling, without getting the joke. This is still 'sharing a joke'-- the emotional experience had by the teller, but not interpretively sharing a joke.

Also, just because you don't get the deep processing in the moment of what's coming in (and it needs to get beyond the literal to the level of processing for relative/personal significance to hit as a joke), this doesn't mean you can't, yourself, in your own processing luxury, come out with a joke, consciously or preconsciously, and for the joke to be fairly intact. Again, too many stereotypes slip unquestionably into 'fact' and it's very two dimensional thinking. Again, not all people with severe Exposure Anxiety labeled 'autistic' have information processing problems. Most do but some, even some apparently 'severely autistic' do not. We need to get that clear. Those who don't have these information processing problems but are severely crippled by the social-emotional developmental problem of Exposure Anxiety would likely have no more problem with jokes than the non-autistic person.

Biklen: I should add, Asperger granted that 'when making puns,... autistic people sometimes shine, and may even be highly creative,' demonstrating 'simple word-play,' 'sound associations,' and 'precisely formulated, truly witty remarks' (p. 82). Can you suggest why this might be the case for some people?

Williams: These rely on right-brain 'pattern' perception more than left-brain 'interpretive understanding.' That's quicker to put together and you don't need the depth of processing to get to a result.

Biklen: You have written about the value of labeling objects and even actions associated with objects as a strategy for teaching and learning communication. You even relate teaching of language to children with autism to some of your own experiences in learning second languages. It would be useful if you could describe how this might work in a home or classroom with a particular child you might have observed.

Williams: I think I wrote about this earlier. But essentially, once labeled, these labels would be read out loud quietly to oneself as objects were utilized. Even verbs can be on cards and used for each action (i.e., 'spin' gets spun, 'run' runs, 'jump' jumps, 'go' goes, etc). Materials such as wood, plastic, metal, etc. would be scratched or tapped for their texture or acoustics in mapping the connection between word and experience. I used this in teaching a Chinese girl English. It is experience-based learning, learning through doing.

Biklen: Sometimes I have observed an adult with autism engaging in compulsive actions (e.g. going around a room touching certain items) and not responding to opportunities to communicate in speech or writing/typing. Lots of times such actions get interpreted by others as evidence of disinterest or, worse, as evidence that the person lacks the ability to understand what has been said to him or her. Your thoughts on this would be very helpful.

Williams: I already wrote about avoidance, diversion, retaliation responses, but also keep in mind that if people have a lack of right/left hemisphere integration, the left may be interested in one activity (i.e. communicating) and the right interested only in checking out the pattern/rhythm/smell opportunities in the environment. If they operate independently, they can compete without one able to easily stop, sometimes even perceive the other.

Biklen: One of the more difficult actions to interpret from a communicative standpoint is self-abuse. I have observed some people with autism who have injured themselves, for example by banging the head on the wall, by

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punching a wall, by biting the base of the thumb, and by gouging arms, legs, and torso. How are we to interpret such actions from a communicative standpoint?

Williams: The emotionally blackmailing defensive warnings of the defensive self (i.e., Exposure Anxiety) may be dominating what we see, but this is not necessarily the self any more than the unintended movements of the person with cerebral palsy are intentional self expressions. Exposure Anxiety may be saying 'back off or I'll hurt myself and make you back off' and to protect the self, we shouldn't be held ransom, letting this over protective prison warden win, but we should take the clear message that if we want to help the self we may need to work in an indirectly confrontational way, even asking (in an indirectly confrontational way) the defensive self if it will back off and let the self answer for itself for a moment.

Biklen: We have discussed problems of limited speech, but there is another interesting phenomenon where some people with autism write in stylistically interesting ways, sometimes using highly formal constructions, unusual sequencing of words, alliteration, highly visual imagery, and so forth. Asperger was quite taken by this, for to him it was surprising, particularly when the unusual utterances were ones he had "suppose(d) to be totally outside the sphere of these children (p. 71).

Such expressions could be at once 'accurate and perspicacious, but also,... often quite abstruse' (p. 71). A friend of mine types in the most wonderfully image rich language, in effect painting pictures with each sentence; at times it takes me some minutes to grasp his meaning, for reading his prose is very much like reading poetry. I'm interested in how you might interpret this kind of distinctively stylized writing in what for other people would be ordinary communicative situations where less interesting and compelling communication often predominates.

Williams: The flying dream speak of the right-brain self is different to the dry logical desert of the left-brain self embedded in the plodding stifling clay of conscious awareness. What I have learned as one who has such lack of left-right integration (whose brain cities have a shattered bridge) is that the world wants mostly my dry desert speak which they understand. This saddens me as it is the right handed writing from the lefthander. I am sure you can understand my stark and clear living example here. But you are talented and experienced in walking the boundaries of two worlds, my friend.

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"I Have Always Loved These Guys, But Now I Respect Them"

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A New Collective Consciousness: Supporting People with Autism to Lead Ordinary Lives

BY LAURA BRODERICK

Jay Nolan Community Services has been providing services to people with autism since 1975. Over the past decade Jay Nolan Community Services has embarked on a journey of organizational change both structurally and philosophically. We began this journey because we discovered that the traditional practices and approaches to supporting people with autism that we used to subscribe to did not work, (e.g. behavior management/programming, congregate programs [group homes, day programs] and a philosophy which focused on autism to the exclusion of the person beneath the label).

What we have discovered along the way is a growing collective consciousness about how to understand and support people with the label of autism that departs significantly from traditional schools of thought. This paradigm shift entails a whole life holistic approach to supporting and assisting people who have been labeled with autism. The shift entails understanding autism in a new light. This shift has led to a significant positive change in the quality of peoples' lives. We want to share what we have learned in hopes that others may begin to see people with autism in a new light.

We started with listening to people with autism.

From listening to people with autism we have begun to learn what autism feels like for the person. People have told us that they sense and perceive the world differently. They have told us that each person with autism is unique, sensing and perceiving the world in their own unique way. Some people are over sensitive to noise; some people are under sensitive to noise. Some people are tactilely defensive; some people love to be hugged and touched.

Regardless of how the senses affect each person, they have told us that sometimes the world is sensorially overwhelming and, therefore, the person with autism engages in idiosyncratic behavior in order to tune out the overwhelming aspects. People have told us that sometimes they behave the way they do because it is the only way they have learned to cope with the world around them. "I hit myself to tune out the noise." "I banged my head against the wall because my ears hurt." So we have learned to understand how each person perceives the world, and help accommodate them so that they can cope with the world in all of its chaos.

We have learned that most people with autism cannot communicate with ease in traditional ways. They communicate in ways that are efficient and effective, but not necessarily appropriate and socially acceptable. We have learned, however, that when we offer new, more appropriate ways to communicate which are just as efficient and effective, people have shown us that they will use these new skills. We have learned to listen to what people are saying regardless of how they are saying it. And when we listen keenly and carefully, people don't have to work so hard or act out to tell us what they need.

People with autism have taught us that many of the beliefs about people with the label of autism are not true. People with autism can love and trust and show affection. People can form lasting friendships and relationships. People with autism have demonstrated time and again that if they have the right support person, they will learn and grow. And conversely, if they are matched with the wrong person, the opposite will result.

We have learned that matching is the key. People should be together because they have common interests. People should be together because they see the gifts in one another. Every person with autism has gifts; the twinkle in their eye, the way they smile or laugh, their passion for bowling or record collecting, their amazing memories. We have seen that no matter how challenging a person's behaviors may be, there is always someone out there who can look beyond the challenges and see the gifts that the person has to offer. Giftedness is at the heart of relationship. When we are able to see the gifts that people have to offer, and we focus on nurturing and developing peoples' gifts, people with autism flourish.

People with autism can work and contribute to the world around them. People enjoy a greater sense of self when they work. People enjoy a sense of belonging. People enjoy earning money. People enjoy contributing. People can have positive and valued roles.

People with autism can learn. People with autism never stop learning. There are people in the world that say people with autism can't learn, especially when they become adults. We challenge those who make these statements to meet some of the people we support. Linda has been given an IQ score equivalent to an 18 month-old-child, and yet, she has a paid job, she has a volunteer position, she is able to maintain a home of her own, and she is able to perform most self help skills with assistance or reminders. She is able to shop and dine out. She is able to now tell us when she is in pain or angry. She has learned to ask for help when she is in pain. She has learned to cope with her anger in more appropriate ways. She

Over the past ten years, and with this new enlightenment from people with autism, we find ourselves offering apologies for our ignorance and misguided efforts of the past. If you want to understand autism, look to people with autism. People with autism are the experts on autism (and their parents and siblings, too).

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continues to learn and grow everyday, despite her label and her IQ score.

People with autism can share ordinary experiences in ordinary places with ordinary people. And when they do, they have the opportunity to learn and model typical behavior. They have the opportunity to have rich, meaningful, and colorful lives filled with laughter and tears, new experiences, hard experiences, life with all of its ups and downs, hardships and beauty.

People with autism have feelings like everyone else. People have told us that they don't like that they appear different to others. They don't like to be stared at or treated differently.

At the same time, people with autism have told us that they wouldn't want to not have autism. "This is who I am." People with autism have depression. People with autism have experienced post-traumatic stress disorder after being abused in institutional environments or by the very people in charge of their "care." People with autism can have mental health issues in addition to their primary label. People with autism can love and hate, lie and be brutally honest. People with autism are cognitively and emotionally aware.

People with autism have taught us that they are incredibly patient and forgiving. After years of behavior modification, punishment, institutionalization and medication, people with autism still trust and smile and look to others for guidance and support. Our nation could learn a lot from people with autism about resiliency. People with autism seem to have a solid sense of self regardless of their life experiences.

The lessons from people with autism are many, and continue to astound and astonish those of us who have been blessed by their presence and gifts. Over the past ten years, and with this new enlightenment from people with autism, we find ourselves offering apologies for our ignorance and misguided efforts of the past. If you want to understand autism, look to people with autism. People with autism are the experts on autism (and their parents and siblings, too).

Over the past ten years we have been providing individualized and personalized supports to persons with autism in the form of supported living arrangements, individualized, full community day services, and individualized family support services.

As a result of this shift in thinking, peoples' lives have changed significantly. People who had some of the "worst reputations" in the State of California for engaging in challenging behaviors no longer merit this label. People are leading ordinary lives in ordinary places with ordinary people.

This article was written by Laura Broderick. Laura is the Director of the Supported Living Program at Jay Nolan Community Services. She has been with Jay Nolan Community Services for twelve years.

If you want to learn more about Jay Nolan Community services, please feel free to visit our website at www.jaynolan.org. If you want to learn more about inclusion, please visit the folks at Inclusion Press, http://inclusion.com. If you want to learn more about this unique approach to supporting people with autism or the label of challenging behavior, read Dr. Herb Lovett's book, "Learning to Listen: Positive Approaches and People with Difficult Behavior."

Jay Nolan Services subscribes to the following philosophy and framework which guides its work:

- ❖ Treat people with dignity and respect.
- ❖ Listen to people.
- ❖ Give people power and control over their lives to the greatest extent possible.
- ❖ Focus on peoples' gifts, and what people are good at, and develop services and supports to nurture the development of these gifts and abilities.
- ❖ Help people communicate through a variety of means, including assistive technology.
- ❖ Develop a Circle of Support around people, assist people to develop friendships and relationships.
- ❖ Get to know people in the context of their whole lives.
- ❖ Assist people to lead ordinary and valued lives.
- ❖ Help people to reach for their dreams and aspirations.
- ❖ Assist people to have a sense of belonging in their community.
- ❖ Assume that people are competent.
- ❖ People have the right to be free from pain, coercion and cruelty.
- ❖ People are entitled to live rich and full lives with dignity and respect.
- ❖ Assist people to develop competencies and learn new things.

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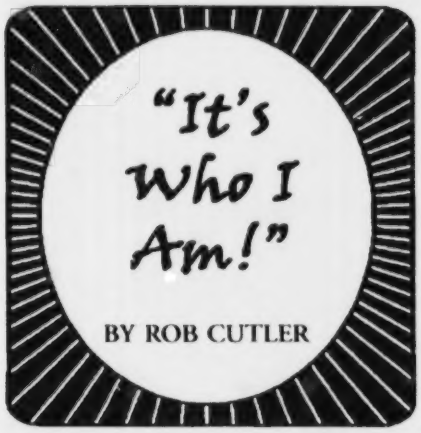

Robert Cutler is President of the Autism National Committee, and serves on the Massachusetts State Advisory Committee to the Department of Mental Retardation, the New Hampshire Autism Task Force and the Board of the Herb Lovett Foundation. He is a man with autism and he lives in his old neighborhood close to his family.

When I was younger, I had words that I could see but couldn't say. Until facilitated communication (FC) came along, I was considered dangerous and a behavior problem. My acting out was a cry for freedom. I could always think, but my words couldn't come out of my mouth. What a difference life has become since I started typing. People started looking at me differently.

Facilitated communication is a tool of power. FC has provided me with the tools I needed to gain freedom from controlling groups. I was not "cured" by FC, but I was put on an even keel. Communication is a right, but because of fear, FC is controversial.

Communication is more than sound coming out of your mouth. It's thoughts and ideas and the forming of opinion. Our brain thinks all the time, but the difficulty comes in forming our thoughts into sounds you call speech. With augmentative devices and training, I was able to express and show my intelligence. I would hope that all could receive the choices and opportunity to use this communication to finally take the guesswork out of what people with autism need and want in their lives.

I type words to help you understand that I have a mind that's not blind, but sees completely. I think, but I process information at various speeds. The weather and being comfortable in my physical environment are keys to my successes and failures, too. I try to express how I feel, but sometimes mixed messages come out in my words. Why? I don't know. I only know that facilitated communication is for me. I think a time will come when FC users will teach others how to FC. I dream of this day, for the sake of the voiceless people.

I have learned that my job is to show there are positive alternatives that work better than those which control and demean people with autism. I am a good man who likes to help people. I enjoy this part of my life. My goals are to promote people with autism as they are — loving, caring, and intelligent human beings who are not blind, but can see. I think for myself, yes.

If you don't understand a child with autism, call a person with autism in; we live autism everyday. I want you to know we love, have emotions and even cry. I get angry because people think we are emotionless, non-humans. We never lie, but sometimes I feel being "normal" means you lie and can get away with it.

It is important to understand that a glossed over treatment program harms the person with autism. If you are talking about money, then you should look at whether you are looking to control or nurture growth in the child. Are you looking to give kindness and love, or in creating robots? Is accepted practice always in the best interest of the person with autism who is receiving the treatment? Be wary of data that appears to indicate progress when it merely measures compliance.

It's a simple equation: subtract the institutions, add people in their home communities with real homes. You then divide the talents each one offers, multiply the joy and love and take the access and spread it across the earth.

I hope you take a look at the environment you expect us to learn in and you will soon see why we act out and cannot sit and stay in our chairs. Your rooms have lights that make noises that cause a severe distraction in our learning. You give us chairs that are quite uncomfortable due to slats in the back which over-stimulate our body. Is the room too bright? Is your home autism-proof? You must be scratching your head by now. Look at where we sleep. Is our room away from traffic? Also, if children live next door to you, move our room to the opposite side of the house. Does our room have a rocking chair? It should. Does our room contain what we need, or did you create it to look normal?

I may say things that you may disagree with. That's good. But there are issues that have no compromise — restraints, pain, forced to stay in group homes and institutions — for these, there is no compromise. The use of each of these must be ended. The professionals need to mingle with the common folk and work on issues around deinstitutionalization and ending the use of restraints and show real changes.

Should a person with a disability be allowed to stop their treatment without parental consent if they feel the pain is too much? Yes! I feel there needs to be more money vested into people who suffer from post-traumatic stress disorder because of being sent to institutions. They were sent to institutions because they were different and society wanted not to help, but hide us.

I want to tell you something personal: terrorism happened daily at the institution. Staff were controlling and we were frightened. Suicide is a thought I had while in the institution and in group home life. I was not the only one who suffered.

I have survived and daily recover from treatments which the National Institutes of Health and the National Institutes of Mental Health allowed to be used on me; they were wrong.

You don't understand autism, but you used behaviorism to try and destroy my will, but I hung on to my sanity. I will not stand by

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"It's Who I Am!"

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another day and allow another person to be hurt or abused because you don't understand the autistic mind. We are human! Get over it! Learn from us. We all have differences but all have some similarities.

I get frustrated because agencies refuse to close institutions down. It's a simple equation: subtract the institutions, add people in their home communities with real homes. You then divide the talents each one offers and multiply the joy and love and take the access and spread it across the earth.

In the best of so-called booming economic times, everyone wasn't set free from institutions. Now the resources are scarce, and they keep pumping gas into the Edsel-like institution.

I call upon TASH to make the closing of institutions their main theme in 2003. I want you to help get a bill through Congress, the Dybwad bill. It will state that monies presently spent in institutions will shift to community 20% a year. After 5 years, freedom! Then they begin life.

I dream of a day when all discrimination finally ceases against children and adults with disabilities, including autism. No child or adult should ever be discarded to an institution or developmental center. I dream a day when institutions close and people live together helping each other! Yes.

Someone can figure it out. Add the money, subtract the politics, multiply new homes and divide them across the country into their neighborhoods.

Many across America are prevented from giving their treasures due to being held against their will, locked up for committing no crime. I know I'm suppose to tell you who I am, but my message is what I feel. It's who I am! Yes!

NLM Foundation Meeting on People with Autism as Self-Advocates

BY SUE RUBIN

It's very interesting to examine why people with autism who use facilitated communication are not more active in the self-advocacy movement. We people have major problems with organizing and regulating our sensory, motor, thought, emotional and other systems (i.e. movement differences and disorders) as Anne Donnellan and Martha Leary have been saying for years. You might wonder what sensory-motor problems have to do with self-advocacy. The answer is in the cerebellum. According to Margaret Bauman in The Neurobiology of Autism (p.136-139), the cerebellum of people with autism is abnormal. This explains a multitude of our problems, including the inability to plan ahead (Bauman, p.138).

The relationship between movement and thought is extremely interesting. When I read the article, *"The Bodily Basis of Thought"* by Jay A. Seitz, (http://york.cuny.edu/~seitz/newideas.htm), I was shocked by the ability to explain autistic problems as a result of neurological abnormalities especially in the cerebellum. Actually, I can see all of my problems are the result of the cerebellum abnormalities.

According to the Seitz article, "recent findings indicate reciprocal and parallel neural pathways between the cerebellum...and the frontal cortex where working memory and executive functions such as planning, monitoring, task management and focusing attention occur" (p.5). Problems in the cerebellum cause "cerebellar cognitive affective syndrome" [which] is linked to disturbances in language (e.g. agrammatism), personality (e.g. blunted affect), spatial cognition (e.g. deficits in visuospatial memory), and executive functions (e.g. difficulties in planning) as a result of disruption of network connections.

We people with autism have problems initiating actions so even if we want to do something for the self-advocacy movement or anything else, we can't. This really is not because we are lazy or disinterested, it is because of the neurological abnormalities. Again, according to Seitz, basal ganglia defects and deterioration of the substantia nigra, locus ceruleus, and raphe nuclei in the brainstem that upset dopamine pathways, result in cognitive as well as motor deficits. ...The ability to shift behavioral set, that is initiate action, underlies the production of novel behavior or the amalgamation of patterned behavior into novel sequences...repetitive stereotyped movement patterns (e.g. obsessive-compulsive behavior...) indicate the malfunctioning of this system (p7).

The amygdala is also abnormal in autism according to Margaret Bauman (p.130). In the Seitz article, he writes "with regard to motor initiation, voluntary movement selection and initiation form an embedded system consisting of the rostral portion of the cingulated motor area which is innervated by the amygdala and ventral striatum,....(p.9)

The neurological elements determine what we are able to do without outside intervention. Just like facilitation being necessary for us to communicate, we need assistance from the outside to enable us to execute plans. In California, we receive services from the state through the Department of Developmental Services' Regional Center System. Under this system we each have an IPP or Individualized Program Plan which is like an IEP for adults. I don't know how other states work, but I propose that we include self advocacy as part of the IPP.

Perhaps we also should recognize that our self-advocacy does not have to look exactly like other people's civil rights advocacy movements. Several of us give frequent presentations at universities, inclusion conferences, supported living conferences, and self-advocacy conferences. We reach a lot of people when they see us presenting with FC. That is a self-advocacy statement in itself.

Sue Rubin is a self-advocate diagnosed with autism and moderate mental retardation. She was educated in segregated special day classes. At age 13 she was introduced to facilitated communication and, over the years her skillful use of FC has grown. Sue graduated from Whittier High School as a fully included student with a 3.98 GPA and scored 1370 on her SAT. Currently she is a student at Whittier College.

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Language Is More Than Speech

BY MORTON ANN GERNSBACHER

I'm very fortunate. I hold a named professorship at a major research university. For the past twenty years I have investigated human cognition and language. My doctoral training occurred during a time so beyond the "cognitive revolution" that I could take for granted the assertion that many aspects of cognition are not observable in overt behavior.

My first professorial position allowed me to rub collegial elbows with cognitive-science greats such as Michael Posner, who coined the term "covert attention" (which in layperson's terms means that the direction in which the eyes are oriented does not always indicate the direction of the person's attention).

In my research I use covert laboratory techniques, such as functional brain imaging, to explore human cognition and language. Simply put, this means that to investigate, for example, how people understand language, I have never had to ask participants in my experiments to point to an object, to match pictures of objects, or to pronounce the name of an object. I use more covert techniques.

Because I have for over two decades taken for granted the assertion that many aspects of cognition are not observable in overt behavior, because I was imprinted on the concept of covert attention (i.e., the eyes not always indicating where a person's attention is directed), and because I'm a pro at using covert methods to understand human cognition and language, it never dawned on me to question the cognitive competence of my son -- despite the fact that his speech is severely belabored, primarily vocalic (produced with vowels rather than with vowels and consonants), and extraordinarily sparse. In other words, he is what others refer to as "nonverbal."

Yes, it is true that somewhere around two years after he was given the diagnosis of "autism" and he was still struggling so mightily with speech, I almost -- yes, almost -- bought into the "low-functioning" bill of goods. But I was duped for less than a fortnight.

I knew my son was not only not cognitively impaired, he was cognitively gifted. Despite the fact that he had been considered "untestable" at 23 months of age on a commonly used baby IQ test (the Bayley Scales) and the label "profoundly retarded" had been entered into his records, I knew he was bright; nay, brilliant. It was easy for me: I'm a cognitive scientist.

But the world is not populated by cognitive scientists. I am reminded of a documentary produced by BBC, which presents an extremely talented pre-teenager (who, like my son, carries the label of autism and who, like my son, struggles mightily with speech). Consider the following conversation that occurred between two internationally recognized experts on autism in the penultimate scene of this documentary:

Expert 1: *Such incredible contrast between what goes on inside him and what his behavior is like; it's astonishing, isn't it?*

Expert 2: *Well, he's terribly advanced for what an eleven, twelve-year-old.*

Expert 1: *Any eleven-year-old.*

Expert 2: *One would think he has a very high level of intelligence.*

Expert 1: *As far as I'm concerned, this is one of the most remarkable children that I've ever seen because there is such a huge discrepancy between his absolutely typical autistic behavior. When you watch his actions and his autistic obsessions - wanting to switch the lights on and off, wanting to go and touch everything - everything that he does fits totally into the classic autistic picture and you would imagine that he was actually quite severely learning impaired. And then you watch him with this alphabet board or with his writing and you read his writing which is done independently and you are amazed at the quality of his mind which is much, much brighter and more thoughtful and more mature then any normal child at his age.*

I don't find astonishing the contrast between what goes on "inside" and what appears to go on "outside," particularly when one considers the lenses that autism experts have been looking through for the past couple of decades. I also don't find remarkable the juxtaposition of "autistic behavior" and a very high level of intelligence. It is not merely cognitive science that has taught me this lesson; it is my beloved son.

It would take more than the pages I've been graciously allotted in this newsletter to tell you all that my son has taught me -- and he's only six years old. No, these are not the lessons of interminable patience, enduring tolerance, and unconditional love; those are the skills that my son has had to hone just to deal with the rest of the world (e.g., everyone from the daily child on the play ground who belliger-

I don't want to give the impression that every five-year-old child with autism could, if provided the right accommodations, perform at the level of a sixth grader. Clearly, this is not true. But the lessons I have learned from my son surely apply to every child with autism — that is, if we were to buy into the level of competence and intelligence that appears to be true on the surface, we would be doing that person a great disservice.

Continued on page 27

Language Is More Than Speech

Continued from page 26

ently asks "doesn't he talk?" to the adult who in response to my son's squealing, states -- in front of him -- that she thought she was in the company of an animal).

The lessons my son has taught me I should have been able to learn from the countless scholarly journal articles I have read. But articles encouraging the presumption of competence and intelligence are painfully missing. We scientists have spent far too much time pinpointing what we propose is broken, damaged, abnormal, and aberrant, and precious too little time articulating the wonderment.

As just one example, how about the lesson that language is more than speech? Over 1000 scholarly publications in the field of autism confuse these two terms; I know, I've read them. Language is the mental representation of concepts and the relations between and among those concepts. Speech is merely the physical production of sounds to express language. Just because a person gropes for speech does not mean that she or he "does not have language."

I don't want to give the impression that every five-year-old child with autism could, if provided the right accommodations, perform at the level of a sixth grader. Clearly, this is not true. But the lessons I have learned from my son surely apply to every child with autism — that is, if we were to buy into the level of competence and intelligence that appears to be true on the surface, we would be doing that person a great disservice.

We need to start with the assumption that every individual with autism has a lot more going on "in there" than is easy for us to grasp. We need to start with the assumption that if people with autism are not communicating their competence in ways that are easily understood, new ways of understanding are needed. We need to assume that if people with autism are not performing well on standardized tests, the likelihood is that there's something wrong with the test, not something wrong with the person.

Given opportunities to communicate that work for the individual, all people with autism will challenge us to re-think limiting perceptions. When helped to discover a personalized communication method that works, all people with autism will reaffirm that just because someone struggles to speak does not mean that he/she doesn't understand and process language. And, as the slogan of the Facilitated Communication Institute challenges us to remember, not being able to speak is not the same as not having anything to say.

Admittedly it still hurts when I read an expert saying such libelous comments as that made by Bryna Siegel in a recent USA Today article (in which "they" means people with autism), "It's as if they do not understand or are missing a core aspect of what it is to be human." However, I am fortunate. The hurt quickly turns to anger and then pity -- for those who do not know what I know, both in my lab and in my heart.

Morton Ann Gernsbacher, Ph.D., is the Sir Frederic C. Bartlett Professor at the University of Wisconsin-Madison. Comments about this article may be directed to Dr. Gernsbacher at <MAGernsb@facstaff.wisc.edu>

Reference

Falcon, Mike "Stars 'CAN-do' about defeating autism," USA Today, April 10, 2002.

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Some say its idealism. We say it is our right, our dream, *Our Quest: Opportunity, Equality, Justice*. The idea that individuals should have the opportunity for a fulfilling life of their own choosing was born long ago. Our earliest leaders understood that freedom and choice are the cornerstones of the community, and the key to fulfillment and success for all. Though certainly not a revolutionary idea anymore, far too many people labeled with disabilities are still struggling each and everyday for the right to life, liberty, and the pursuit of happiness.

The TASH Conference is the modern day "Tea Party." Much like this famous event, the TASH Conference mobilizes vast numbers of people, linking folks from around the world together in a common experience of mass popular insistence - Equality, Justice and Opportunity for ALL!. The electrifying information and energy generated at the conference spreads; participants returning home with renewed spirits to stage similar acts of resistance and insistence of their own!

Join over 2500 patriots of the movement for inclusive communities in Boston this December for this exciting event. Send in your registration by August 15th, and take advantage of the Earlybird Discounts! The registration form is located on page 28 of this issue of TASH *Connections*. For information on accommodations and airlines, visit TASH's web site at www.tash.org

TASH 2002 Annual Conference Registration

Org_____ ID _____
Reg _____

- **Fill out one form for each person attending**
- **Payment MUST accompany your registration for discounted early rates**
- **All advance registrations must be received in the TASH by November 22, 2002. After that date registration is on-site only and will have a $40.00 additional fee.**

Please make checks payable to TASH.
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Fax: (410) 828-6706 **Email:** registration@tash.org
Website: www.tash.org **TASH Federal Id # 51-0160220**

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Badge Name:		**TASH Member ID:**	
Organization:			
Address:			
City/ State / Province			
Postal Code		**Country:**	
Phone:		**Fax**	
Email:		**Address type:**	[ ] Work [ ] Home [ ] School [ ] Other
Accommodations Needed:			

A **Membership**
If you are not a current TASH Member, JOIN NOW for $88 for Individual or $45 for reduced rate (income less than $25,000)
This special offer entitles you to register for the conference at the member rate, and includes one-year membership.
[ ] I am a Current International TASH Member #_____
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ADD MEMBERSHIP	International	International & Chapter
Individual	+ $88	+ $103
Reduced Rate	+ $45	+ $60
	-	

B **Conference Registration CIRCLE ONE:**

	TASH Member		TASH Non Member	
	Before August 15	After Aug 15	**Before August 15**	**After Aug. 15**
Individual Registration	**+ $219**	+ $244	+ $351	+ $374
Family Member or Person with a Disability	**+ $39**	+ $84	+ $95	+ $160
Student	**+ $129**	+ $164	+ $219	+ $264
One Day [ ] Thursday [ ] Friday	**+ $119**	+ $154	+ $179	+ $204
Saturday Only	**+ $39**	+ $59	+ $69	+ $89
Personal Assistant—No Charge	*must attend sessions and register with the individual he or she will be supporting*			

C **Team Discounts (must register together-—use a separate form for each person):**
• Groups of 5 or more registering at the same time **OR** Two or more members of the same team (i.e.: a special educator and a regular educator) Subtract **$20** per registrant for group **or** team discount if

Subtract Discount -

D **TASH TECH Pre-Conference Workshops 10:00 AM- 4:00 PM, Wednesday, December 11th**
(registration is in addition to the conference fees)
Register and Pay now and choose later (we'll send you the choices when they are published)
TASH Members $55 Non-members $85.00 Individual with a Disability/Family member $40.00

TASH Tech Fee +

E **Round Table Networking Luncheon – Thursday, 1:00-2:15 PM $20.00 per Person**
(you must purchase a ticket in advance, and please be sure to fill out any special diet requests)

Round Table Lunch +

F **I would like to make a donation to support a self-advocate/parent to attend the conference:**

Donation +

GRAND TOTAL Conference Registration: (Add Sections A – F) =

PAYMENT METHOD: [ ] Check [ ] P.O. (original must be include)
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Registration will not be accepted without payment by check, credit card authorization or with an official purchase order. Payment must be in U.S. Funds only. A $25.00 processing fee will be deducted from all requests for refunds that are received before October 15, 2002. No refunds after that date. $25.00 fee for returned checks or unauthorized charges.

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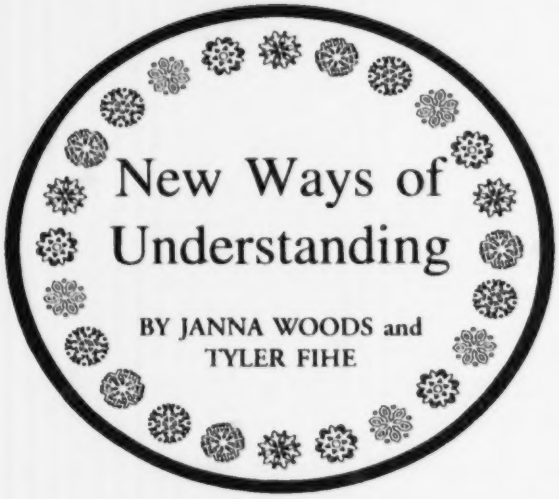

Tyler Fihe is a 16-year-old sophomore in high school. Tyler uses facilitated communication (FC) to speak. "I am a person with autism. Notice the 'person' part came first. In the past people treated me as though I was an empty shell to be filled. Anger filled my life because I couldn't communicate.

When I was six-years-old, my mom started to use facilitated communication with me. I had to overcome fear. I had to learn a new way to communicate. Mom and I practiced 10 minutes everyday until we could type fluently together. I mostly typed at home with mom because I had no FC trainer. Lack of a Training Facilitator was a huge barrier.

Finally, when I was in the 6th grade, I was blessed with an FC trainer. It took until 8th grade to really achieve inclusion. Finding good FC staff is like finding a needle in a haystack.

Since 8th grade, with FC I have learned to speak. I have a Lightwriter (a voice output device). I have lots of friends and a bright future. Getting a voice changed the course of my life."

Janna Woods is a Facilitated Communication Trainer. "In 1992 as I pondered a change in careers (from behaviorist to landscape architect), I was introduced to facilitated communication. This introduction changed my life and now shapes all my interactions with the students I serve.

Learning to be a facilitator not only helped me provide a much needed opportunity for the 'voiceless' students I served, but it also made me reflect and search my heart in an effort to reconcile my past perspectives regarding those with autism. Truth be told, I had to examine some of the deepest, darkest, and ugliest sides of a belief system that kept people oppressed. Worst of all, I had to admit that I participated in this oppression with all the professional rationalizations I could muster. Admitting that I had seriously underestimated my students, participated in oppressing them, and believing that 'I knew what was best for others' was the most devastating professional time of my life.

On the other hand, breaking free of hopelessness and embracing unlimited possibilities energized my spirit and set me on an unimaginable journey that continues day after day, miracle after miracle. My relationships with the people I serve has changed from a 'one way' oppressor conversation to a full partnership that allows both parties to give and take and really connect in ways that were previously impossible.

Communication is the foundation for all interactions. Meaningful relationships develop when each person is respected, valued and embraced as an active member in every interaction. True friendships are born on a level playing field. "Inclusion" moves from being a politically correct thought to a true experience.

All people bring a unique gift and life experience to any interaction. Seeking that gift begins by acknowledging the personhood of an individual first and labeling them last! Facilitated communication is leading me on an amazing journey that I could have never imagined. I am blessed to have a job that I love and to be working with people who enrich my life daily. My life is a blessing and those I serve are gifts!"

Tyler Fihe and Friends Speak Out

Janna Woods (l) and Tyler Fihe were two of the participants of the May 3rd meeting to explore people with autism participating in public policy efforts (see article, page 3).

Tyler Fihe was an active participant in the "Breaking the Barriers" event held May 3 in Boston, Massachusetts. At that meeting, people who use facilitated and augmentative communication, TASH advocates, national disability rights leaders, and family members met to identify the policy issues that are of importance to people who use alternative forms of communication. Working together, the group discussed and planned ways they could address those issues effectively in the public policy arena and how to overcome barriers that continue to thwart the efforts of people with disabilities to speak for themselves.

In preparation for this meeting, Tyler, a high school student who uses FC, took it upon himself to develop a questionnaire which he distributed to friends who also use alternative communication or who struggle with communication difficulties. In the cover letter attached to the survey Tyler said:

"I am writing to you because I am going to Boston to talk about how autism affects our being a force in the world. People continue to make our world limited. I want to bring our voices to the world of decision-makers. Please read my questions and give me your input, so we can be part of the world as the wonderful people that we are."

Tyler's friends responded with gusto. Their answers are full of heart, resolve and urgency. The following answers are composites of many individual responses.

Question: What makes you happiest in your life?

Answer: When I have a voice and get to be included. When I am with Dad and we can talk like father and son. When I'm with people who love me without focusing on my parts that are different. I'm finally able to have a life I can control. When I'm saying what's on my mind and not being controlled by others. Mom makes me happy. Being able to communicate makes me happiest.

Question: What makes you saddest?

Answer: I am sad that I have to move to a group home because my mom needs to work and supports are not available to her to keep me at home. I am saddest being silent and treated like a nonhuman. It breaks my spirit to be thought of as a collateral by-product. When I feel left out because I'm different. I hate being non-verbal and dependent (I hate my stupid mouth). Being disabled and thought of as a waste of money. Without speech I am a vacant body and a burden on my family.

Question: How have you learned to communicate?

Answer: Through facilitated communication. FC is my only method of really communicating my real deep thoughts. I was totally voiceless prior to FC. I communicate through talking and writing. My mom and my dad taught me how to talk and write. I use a Lightwriter, and some gestures and a few words. I use pictures and read words. I had to relearn that I can be something!

Question: What got in your way when you were learning how to communicate?

Answer: People who are facilitated communication skeptics. Professionals with limited training. Stupid professionals — what else can I say, they were morons. Beliefs that people thought I was retarded. Having me talk out loud because it is hard to think of the right words. My body, my school and everybody who thinks I'm stupid. People not believing in my abilities.

Question: How would you change the way you have been treated in the past?

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Tyler Fihe and Friends Speak Out

Continued from page 30

Answer: I want to be valued for who I am. I deserve a real shot at participating with the correct supports and not some lame idiots pretending they know me. I would make them treat everyone with a lot more respect and decency and kindness.

Question: If the government were to design a program for people challenged with autism what would you want it to include?

Answer: Technology. Inclusion with typical kids. Money to train people and higher pay for staff. People like those who know facilitated communication. Control of who works for me and control of my support funds. Knowledgeable professionals that people with autism recommend. A way for everyone to talk and participate. Help us communicate so we feel like human beings.

Question: What frustrates you the most living with autism?

Answer: People's beliefs. No one really understands how frustrating it is not to be understood. Being thought of as retarded. Being limited by the availability of trained staff. My mind is normal but my mouth behaves like it is not part of me. If the professionals are making money off me then at least be knowledgeable and make my life livable. Laughing is the only way to get by the unlivable sadness of silence. . ."

"People continue to make our world limited. I want to bring our voices to the world of decision-makers."

THE POWER OF ASSUMING COMPETENCE

Continued from page 4

❇ Self-advocacy should be taught in school by adults with disabilities
❇ Time and ongoing support to build power
❇ Use of personal stories
❇ Practice competencies of influence
❇ Effective networks
❇ A living wage
❇ Voter registration

Next Steps (Creating the Force)
❇ Identify a group of individuals with autism that is representative of the autism community and bring them together to establish a unified voice that represents the issues of today. Hold a meeting at the TASH Conference in Boston. Focus on:

— Changing the public perception of individuals who experience autism
— Leadership training/mentoring
— Organized public relations/marketing
— Developing a plan and implementing it

❇ Within each state, gather people with autism, both FC users and people who speak in conventional ways to educate the public. Look for opportunities within our communities to speak out about talents
❇ Seek endorsement of the TASH position statement on FC by as many organizations as possible
❇ Involve people with autism who communicate in alternative ways in the same self-advocacy activities as individuals who speak in traditional ways
❇ Model and learn from those who say that they represent people with disabilities — information must come from people with disabilities and their allies
❇ Continue to meet semi-annually or annually to report back on individual successes and current challenges as we do the work of social change agents

Sandra Radisch, a participant from California, concluded the meeting in Boston by typing the following thought, *"Until human diversity is a cause for celebration and not discrimination there will be marginalization. How disturbing that each group has to practically start each time at ground zero to fully assert their human rights. Up until now I have been discouraged by the enormity of the task. Now I say let the work begin. Stay in touch, organize, act, reflect and persist!!"*

(Facing forward, l-r): Janna Woods, Tyler Fihe, Suzanne Maas (standing), Carolyn Nuyens, and Sandra Radisch

TASH NEWSLETTER

Priscilla Newton, *Editor*

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It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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TASH CONNECTIONS

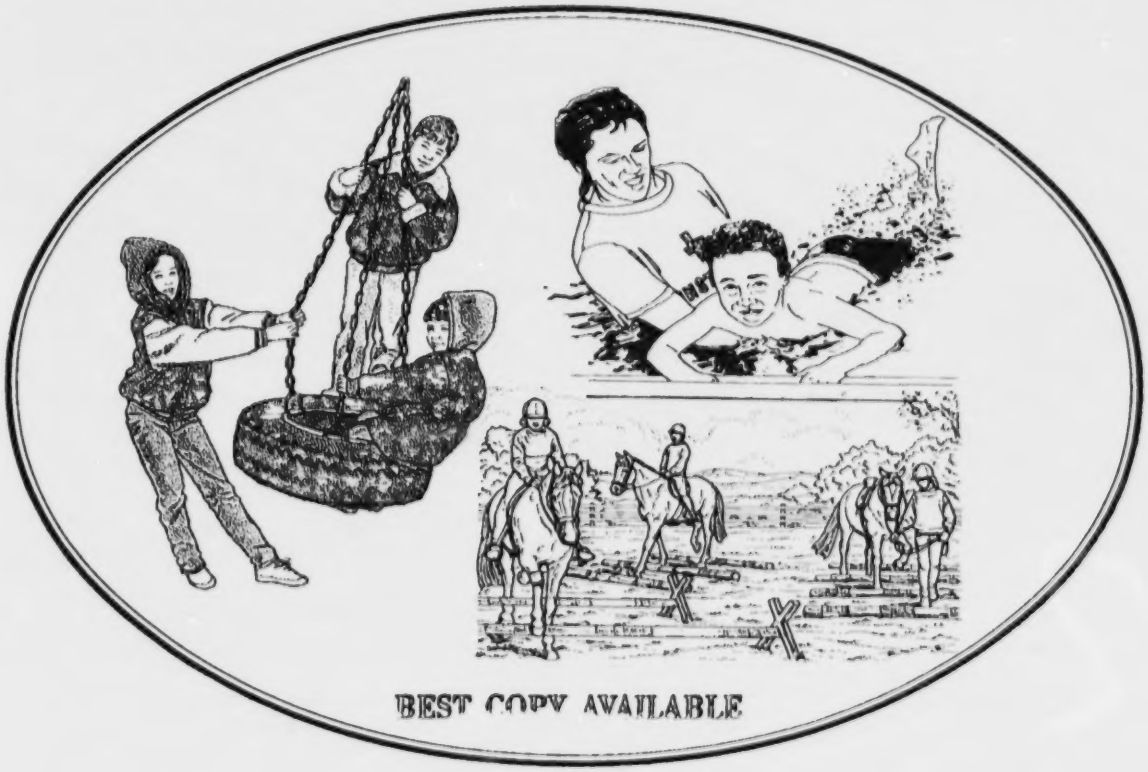
Equity, Opportunity and Inclusion for People with Disabilities since 1975

Inside This Issue

- TASH Executive Board Candidates
- Making Friends Within Inclusive Community Recreation Programs
- Remembering Justin Dart
- Creating Opportunities for Inclusion in Leisure Activities

URGENT!
Dated Material Inside!
2002 TASH Board Election Ballot!

Fostering Friendships through Recreational Experiences



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Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

TASH MISSION

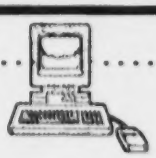
TASH supports the inclusion and full participation of children and adults with disabilities in all aspects of their communities as determined by personalized visions of quality of life.

TASH's focus is on those people with disabilities who:

- Are most at risk for being excluded from the mainstream of society
- Are perceived by traditional service systems as being most challenging;
- Are most likely to have their rights abridged;
- Are most likely to be at risk for living, working, playing, and/or learning in segregated environments;
- Are least likely to have the tools and opportunities necessary to advocate on their own behalf;
- Historically have been labeled as having severe disabilities; and,
- Are most likely to need on-going, individualized supports in order to participate in inclusive communities and enjoy a quality of life similar to that available to all citizens.

TASH accomplishes this through:

- Creating opportunities for collaboration among families, self-advocates, professionals, policymakers and other advocates;
- Advocating for equity, opportunities, social justice, and rights;
- Disseminating knowledge and information;
- Supporting excellence in research that translates to excellence in practice;
- Promoting individualized, quality supports;
- Working toward the elimination of institutions, other congregate living settings, segregated schools/classrooms, sheltered work environments, and other segregated services and toward replacing these with quality, individualized, inclusive supports;
- Supporting legislation, litigation and public policy consistent with **TASH**'s mission; and,
- Promoting communities in which no one is segregated and everyone belongs.



WHOM DO I CONTACT?

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Meetings and Information Resources, at (410) 828- TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 2002 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on governmental affairs, call:** Jamie Ruppmann, Director of Governmental Affairs and Public Policy, at (410) 828-TASH, Ext. 104, e-mail: jruppmann@tash.org
- **For information on newsletter submissions and advertising, marketing and promotions, or permission to reprint, call:** Priscilla Newton, Director of Marketing, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on Research and Practice for Persons with Severe Disabilities (a publication of TASH), call:** Fredda Brown, Editor-in-Chief, at (718) 997-5243, e-mail: fbrowncuny@aol.com
- **Don't forget to visit TASH's web site at http://www.tash.org**

TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. **TASH** actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: **TASH**, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

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2002 TASH Conference

The revolutionary idea that individuals should have the opportunity for a fulfilling life of their own choosing was born long before the American Revolution. Our earliest leaders understood that freedom and choice are the cornerstones of the community, and the key to fulfillment and success for all.

Some say it's idealism. We say it is our right, our dream, *Our Quest: Opportunity, Equality, and Justice.* Though certainly not a revolutionary idea anymore, far too many people labeled with disabilities are still struggling each and everyday for the right to life, liberty, and the pursuit of happiness.

The TASH Conference is the modern day "Tea Party," mobilizing vast numbers of people from around the world in a common experience of popular insistence - Equality, Justice and Opportunity for ALL! The electrifying information and energy generated at the TASH conference spreads as participants return home to share strategies, renew commitment, and create action and synergy surpassed by none.

The TASH Conference is the largest and most progressive gathering in the United States that focuses on the full inclusion of people labeled with disabilities. Join over 2,500 people from around the world and across the street, people for whom the saying *All Means ALL*, are words to live by; who have successfully put the belief of inclusion for all into practice.

BE THERE – December 11 - 14, 2002

Conference Location

Headquarter Hotel: Sheraton Boston

Prudential Center, 39 Dalton Street, Boston, Massachusetts 02199

Direct Phone/Reservations: (617) 236-2000; Fax: (617) 236-1702
For Toll-Free Reservations call 1-888-625-5144 in the U.S. or Canada

All other countries, visit the website for http://www.starwood.com/sheraton/contact/contact_na.html

TASH Group Block Rate

The Sheraton has confirmed the following group rate, available to TASH Conference attendees:

Single Occupancy (one person) $145.00
Double Occupancy (two people) $153.00
$20.00 per night for each additional person
Applicable Boston Sales Tax - 12.45%

Check-in at the hotel is 3:00 PM on the day of your arrival.

The Sheraton will accept reservations under the TASH block at the above rate, subject to availability. After the TASH block has been sold out, or after Monday , November 11, 2002, the rate may be higher. The TASH Conference is a well-attended, popular event - so make your reservations early!

Tentative Conference Agenda

Tuesday, December 10

Registration Open 5:00 p.m. -7:00 p.m.
Exhibitor Set Up 12:00 p.m. - 4:30 p.m.
Symposium on Criminal Justice (1st Day)
10:00 a.m. - 4:00 p.m. (registration for this event is open only from 9:00 a.m. - 10:00 a.m.)

Wednesday, December 11

Pre-Conference

TASH TECH Pre-Conference Workshops
10:00 a.m. - 4:00 p.m.
TASH Chapter Leadership Day 1:00 p.m. -5:00 p.m.
Symposium on Criminal Justice (2nd Day)
10:00 a.m. - 4:00 p.m.
NLM Family Foundation Symposium
10:00 a.m. - 4:00 p.m.
Exhibitor Set Up 7:00 a.m. - 1:00 p.m
Registration Open 7:00 a.m. - 11:00 a.m. and 2:00 p.m. - 7:00 p.m.
Opening Reception 5:00 p.m. - 7:00 p.m.

Thursday December 12

Conference Begins

Registration Open 8:00 a.m. - 2:00 p.m.
Exhibits Open 8:00 a.m. - 6:00 p.m.
General Session 8:45 a.m. - 10:00 a.m.
Breakout Sessions 10:15 a.m. - 12:30 p.m.
Roundtable Luncheon 12:45 - 2:00 p.m.
Breakout Sessions 2:15 p.m. - 5:45 p.m.
Reception 6:00 p.m. - 7:30 p.m.

Friday December 13

Registration Open 8:00 a.m. - 1:00 p.m.
Exhibits Open 8:00 a.m. - 5:00 p.m.
Breakout Sessions 8:00 a.m. -11:30 a.m.
General Session 11:45 a.m. - 1:15 p.m.
Breakout Sessions 1:30p.m. - 5:00 p.m.
Reception 5:30 p.m. - 7:00 p.m.

Saturday December 14

Poster Sessions & Saturday Institutes

Registration Open 8:00 a.m. - 10:00 a.m.
Poster Session Set Up 7:30 a.m. - 8:00 a.m.
Poster Sessions and Breakfast 8:00 a.m. - 10:00 a.m.
Exhibits Open 8:00 a.m. - 12:00 p.m.
Saturday Institutes 10:00 a.m. - 3:30 p.m.

To obtain a copy of the conference brochure, call the TASH Central Office at 410-828-8274 or visit TASH's web site at www.tash.org

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THE 2002 EXECUTIVE BOARD ELECTION

YOUR ROLE IN SELECTING TASH's LEADERS

One of the most important things members of any organization are asked to do is to participate in selecting members of the Executive Board. Now is the time for you to decide who will help provide critical leadership in TASH's social justice movement for people with disabilities. Many important issues and challenges face us - your participation as a voting member of TASH counts more than ever.

Five of the 15 seats on the TASH Executive Board will be re-seated at the December 2002 TASH Conference in Boston. The individuals who appear on this year's slate have made significant contributions in the lives of people with disabilities and have demonstrated leadership in the disabilities movement.

Your vote is critical. Please use the postage-paid, self-mailing ballot provided on page 11, or clearly write "ballot" on the envelope you use. Ballots must be received at the TASH office by **October 28, 2002**. Please use ink and vote for five candidates. Voting for more than 5 nominees will invalidate your vote.

THE FOLLOWING ARE THE NOMINEES FOR THE TASH EXECUTIVE BOARD OF DIRECTORS:

Jacki Anderson

Jacki Anderson's ongoing commitment to include individuals with significant disabilities in all aspects of life has been readily evident throughout the three decades she has been in this field. As a classroom teacher, she spent 10 years working in the first integrated California public schools program for students with multiple disabilities, autism and other health impairments. These students, who had historically been served in institutions or segregated schools, taught her the power of teaching in natural environments, the importance of family partnerships in the educational process, and the tremendous need for both advocacy for effective services and educated support personnel.

These important lessons have been the foundation of her efforts as a trainer, researcher, and facilitator of systems change. She has over twenty-six years experience conducting inservice training activities around the country and has taught for twenty-two years in Special Education teacher training programs at the University of Wisconsin, San Francisco State University, and California State University Hayward, where she has served as coordinator of the masters degree and credential programs in the area of moderate-to-severe disabilities since 1986.

Jacki's areas of specialization include personnel training, inclusion of individuals with significant disabilities, and positive behavior support. She has been awarded funds to pursue all of these interests via research, training, and model demonstration projects and has published the results in textbooks, chapters, and journal articles. She served as Coordinator of the California Research Institute on the Integration of Students with Severe Disabilities (CRI), Director of a series of personnel training projects addressing integration, community intensive instruction and inclusion, and as Training Coordinator for the Rehabilitation, Research and Training Center on positive Behavioral Support, a six University consortium dedicated to developing and disseminating practical technologies for supporting individuals with behavioral challenges in inclusive school, work and community environments. Over the course of this project, she coordinated the development of a comprehensive inservice training model to establish interagency state level training teams. As a result, a network of 26 State teams is working collaboratively to provide training and technical assistance to assist local communities in building the

Continued on page 5

2002 TASH Board Election

Continued from page 4

capacity to provide effective and respectful positive behavioral supports in inclusive settings. She also serves on a variety of national, state, and local committees and advisory boards.

Jacki has been an active member of TASH since 1979 and of CAL-TASH since it was founded in 1982. She is past president of the CAL-TASH board, (board member since 1989), board member of TASH since 1998 and is currently serving as Chair of the Executive Committee. Jacki would bring to the board an understanding of and commitment to the relationship between TASH and the chapters. She has a genuine interest in the organization's continued efforts in the areas of advocacy and the dissemination of information via the journal, newsletter and efforts to influence legislation and policy development that support the rights of individuals with significant disabilities to be active and respected members of our society.

Wanda J. Blanchett

Wanda is an active TASH member who has boldly undertaken controversial issues of sexuality education, HIV/AIDS education, and issues related to meeting the needs of non-heterosexual individuals with significant disabilities. For over 15 years, she has worked in community and public school settings to promote the inclusion of individuals with disabilities in all facets of life. She has worked diligently as a direct service provider, teacher, and teacher educator to increase participation of individuals with special needs in their local communities and to improve educational programming and outcomes for people with disabilities.

Wanda's commitment to empowering persons with significant disabilities to determine their own destiny is informed by her work in the 1980s as a direct service provider for recently deinstitutionalized individuals in the state of Arkansas. Specifically, she helped to facilitate their transition into independent living settings, employment, post-secondary education and all other aspects of adult life that were important to them.

Wanda is an advocate for inclusive education and quality educational programming for students with special needs. Her pledge to improving educational programming and outcomes of students with disabilities dates back to her classroom teaching experiences in the Delta region of Arkansas. As a practitioner, she taught students with disabilities in an elementary public school setting and served as a consultant to regular classroom teachers long before it was considered "best practice." She provided technical assistance to general education teachers that enabled them to meet the needs of their students with disabilities within the general education curriculum. Although Wanda found her role as a practitioner extremely rewarding, her desire to have a more direct impact on improving educational programming and outcomes of students with special needs led her into teacher education and research.

Wanda is currently an Assistant Professor in the Department of Exceptional Education at the University of Wisconsin-Milwaukee where she is involved in teacher preparation and research. Her research focuses on issues of sexuality, urban teacher preparation, and the role of race, class and gender in special education. Additionally, she has published several articles in special education journals and made a number of presentations at TASH and other professional conferences. She is currently chair of TASH's Development Committee and a member of the Newsletter Advisory Subcommittee.

Wanda has been a TASH Board member since 1999 and is interested in continuing to serve on the Executive Board for three reasons: she would like to utilize her practical and professional experience to further the mission of TASH; she wants to ensure that TASH continues to be viewed as a leading advocacy organization that is committed to diversity in all of its many forms; and she would like to work within the framework provided by TASH to challenge attitudes, institutions and policies that prevent individuals with significant disabilities from expressing themselves and achieving their goals.

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2002 TASH Board Election

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Beverly Fields

"TASH has been an incredibly powerful influence in my life and the life of our family over the last several years. I'm thrilled to be nominated for the TASH board and welcome the opportunity to serve.

My husband, Carl, and I have two teenage children. My son, Paul, has learning disabilities and my daughter, Maria, has significant disabilities. I've been a nurse for 25 years with experience in ICU, psychiatry, and ambulatory medicine.

My connections with TASH started and grew as a result of my growth in advocacy for my daughter. In 1997, I became aware of Maria's legal rights and her need for an appropriate education in the least restrictive environment. As disagreements arose between our family and the school district over many aspects of Maria's education, my education in advocacy began. Our family pressed the school system to provide an appropriate education, and the school system repeatedly failed. Although Maria bore the brunt of challenging the system, our entire family learned firsthand about the pain of discrimination, segregation, ridicule, and injustice.

My education in advocacy expanded through those turbulent years. I learned about legal rights, pain and perseverance, positive behavior support, best practice support strategies in inclusive education, and most importantly, components of effective advocacy. I learned to celebrate the small victories and to take nothing for granted. I learned to rely heavily on the supports that surrounded me, but I also realized that I needed to learn and grow from their expertise. The ongoing support that our family needed to challenge the system came from a variety of individuals many of whom, I discovered later, were TASH members. Commitment and dedication to inclusion were consistently demonstrated by each TASH member who supported us. I continue to be in awe of these wonderful advocates and have the utmost respect for these people who have stood with and supported our family in our difficult journey over the years.

In 1999 I attended my first TASH convention. There I gained a more global perspective of the struggle we were having with our local school district. I began to feel and experience what the movement of TASH is all about. Not only was the TASH conference informative, it was energizing! I returned home with revitalized energy and commitment.

In December of 2000 we came to an agreement with the school district that ended the due process. As a part of that agreement, an expert in inclusion was hired by the school district to provide consultation. The adversarial climate of due process slowly shifted to a climate of collaboration. Other key players, several of whom were TASH members, also contributed to the growth in awareness, collaboration, and the actual "how to" of inclusive education at school that Spring.

The movement to develop a more inclusive approach to education has continued over the past year. Positive changes are occurring not only for Maria, but also for other students. For the first time in her life, Maria enjoys going to school and is learning new, useful skills in general education and in the community. School and home are in ongoing collaboration, working to increase Maria's participation in general education and to increase her opportunities for developing friendships.

As I've become a more knowledgeable and confident advocate, I've worked to support other families in the IEP process as a volunteer advocate. I participate in several local school and community organizations. I'm a graduate of Missouri's Partners in Policymaking. I'm an active supporter and team member of the TASH Million Dollar Drive.

If I'm selected for the TASH Board, I'll bring to the board the same enthusiasm, perseverance, and dedication that I've had in my advocacy for my family and in my local community. I believe I can bring the needs, perspective, and support of parents to TASH. Working together and supporting each other in our struggles for inclusion is critical. Parents need access to information and to be connected with other parents, with self-advocates, with educators, and with other advocates. With support, parents can partner with other advocates and be powerful contributors to the mission, values, and goals of TASH."

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2002 TASH Board Election

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Ming-Gon John Lian

"I feel extremely honored to again be nominated for this year's election of new board members! I became a TASH member in the 1970s and was a member of the Texas-TASH while I was still a student. Early in the 1980s, I was encouraged by the TASH Board to join the effort of enhancing programs and activities relating to cultural and linguistic diversity in TASH. I will always treasure the opportunities I have had to serve as the chair of the Asian/ Pacific Subcommittee (1984-1994), the chair of the TASH Committee on Multicultural and International Issues (1989-1991), a member of the Community Living Committee (1987-present), a member of the Elections Committee (1990-1991), a reviewer for the TASH Conference (1989-present), and an ex-officio member of the TASH Board (1990-1991 and 1998-present).

I have also actively participated in state chapter (Illinois-TASH) activities. I was a board member (1990-1993 and 1999-present), newsletter editor (1991-1993), and the chair of the Volunteer Committee at the IL-TASH Conference (1999-present).

The major reason I am a loyal member of TASH is because I believe in advocacy and justice for all individuals in an inclusive community. Being a faculty member in teacher education at Illinois State University, my commitment and effort to serve on the TASH Board will include sharing of my 23 plus years of TASH experiences, teamwork, and advancement of policies and services for underrepresented persons, as well as promising practices in the schools and in communities."

Barbara Ransom

Barbara Ransom identifies herself as a legal advocate for persons with disabilities. She was waylaid from a career in computer law by Nancy Zollers, and received her tutelage in disability rights advocacy from Frank Laski, Tom Gilhool and Judith Gran. Barbara has practiced at the Public Interest Law Center in Philadelphia (PILCOP) for 12 years, using federal laws, including ADA; IDEA; Rehabilitation Act, and state human rights laws to ensure the full integration of persons with disabilities.

Barbara's interest in disability rights and advocacy issues is also personal. She had two brothers, Walter and Kenny, with physical and learning disabilities. Although Barbara is a certified school teacher with a masters degree in counseling psychology, it was not until she entered the legal profession that she began to understand and appreciate the hurdles that her brothers had to overcome to achieve their independence.

Barbara continues the PILCOP tradition of advocating for systemic change so that all people are valued. As a member of the TASH Board she hopes to increase TASH's involvement in the area of criminal justice by including persons with disabilities as a protected group under the National Hate Crime bill. Barbara would also like to help TASH take a leadership role in assuring that the international community responds to the challenge of full inclusion.

Sue Rubin

"My name is Susan Rubin. I am a 24-year-old woman with autism. I have been motivated to run for the TASH Board due to the fact that I believe the people representing TASH should be those who not only advocate but also live with a disability each and every day. I can offer insights that perhaps other candidates may not be accustomed to dealing with.

My main purpose for being a member of TASH is to help further educate those with misperceptions of what a person with a disability can achieve. As an advocate, I am dedicated to making a significant contribution to the lives, education, research, and welfare of those with disabilities and their families.

I am currently working towards my degree at Whittier College. I am a junior though I have been attending since 1997. This has been a long and tedious journey, yet it has shaped me into an individual with great pride in

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2002 TASH Board Election

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my accomplishments. I have participated in over fifty presentations to groups at conferences, colleges, and social service agencies, including five times as a keynote speaker since 1992. Just to name a few accomplishments I have been honored with thus far: Supported Life Institute Award; Wendy, F. Miller Outstanding Individual with Autism Award from the Autism Society of America; and recipient of the CalTASH-Mary Falvey Outstanding Young Person Award. I was privileged to carry the Olympic Torch as a Community Hero in the 1996 Olympic games.

I am honored to be nominated for the TASH board and am confident that I will contribute a great deal of leadership and commitment to TASH's objectives, offer unique perspectives and be part of the future of TASH's dedication to individuals with disabilities."

Leslie Seid Margolis

"I am honored to be considered for a TASH Board position. As an attorney at the Maryland Disability Law Center, Maryland's protection and advocacy agency, for nearly 17 years, I have engaged in individual and systemic special education advocacy and in special education legal policy work at the local, state, and federal levels. As the parent of an 8-year-old child with profound physical and cognitive disabilities who is fully included in a Baltimore City public school classroom, I also have a personal connection to disability issues.

As a longtime TASH member, I embrace the values that form the foundation of TASH, and work for the day when there will be sufficient supports and services available to ensure that all persons with disabilities are able to live in their home communities, attend neighborhood schools, and be employed competitively and productively without the need for extensive advocacy services.

Professionally, I have represented children with disabilities in individual special education cases and in juvenile court foster care proceedings for many years. Some of my most satisfying cases have involved moving children out of segregated settings into their neighborhood schools and communities.

I spent many years co-counseling a major systemic reform special education case against the Baltimore City public school system. I co-founded and continue to chair the Education Advocacy Coalition for Students with Disabilities, a group of 25 individuals and organizations concerned about special education issues in Maryland. I have served, and continue to serve, on a number of state task forces and advisory committees related to special education, and on other disability-related boards and councils. Currently, I am a member of a state task force charged with the development of regulations regarding restraint and seclusion of students in schools. The task force was appointed in response to legislation I drafted in an effort to limit and regulate the use of restraint and seclusion in schools. Until now, Maryland has had no statewide law, regulations, or policies regarding the use of these highly aversive behavior controls.

At the national level, I have worked for many years to reform the federal special education monitoring process, and have participated actively in a national workgroup that has designed and promoted a system of focused monitoring and active enforcement. The Department of Education recently agreed to adopt this system.

As a parent, I understand the reality of raising a child with severe disabilities. I understand that in some ways, the ability to pursue inclusive education for my daughter and to be a firm proponent of inclusion in all aspects of life is a luxury denied to many other families who do not have meaningful choices or options for their children.

Inclusion should not be a luxury, and it should not be something for which families have to fight. If elected to the Board, I would seek to have TASH use the expertise and experience of its members to develop a plan to increase the availability of supports, services, and resources so that more individuals with disabilities and more families will be able to choose inclusive living arrangements, schools, and jobs.

As a Board member, I would also strive to cement the relationship between TASH and the protection and advocacy system and other disability organizations. At a time

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2002 TASH Board Election

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when disability protections are being narrowed by courts and are jeopardized from every direction, it is essential that we find as much common ground as possible and work together to preserve the gains we have made and lay the groundwork for future progress."

Scott Shepard

"I am truly honored and humbled to be selected as a nominee for the TASH Executive Board. I have been learning from people with severe reputations and their families for over 20 years in the course of providing direct support services. Much of the work and research done by TASH members has shaped and guided me in the support I provide to people.

Some of the work I am involved with now includes coordinating state training in California on Positive Behavioral Support through the Rehabilitation, Research & Training Center on Positive Behavioral Support; currently serving as a Cal-TASH Board Member, serving on the Vendor Advisory Committee for North L.A. County Regional Center; and as a committee member for the Santa Clarita Mayor's Committee for Employment of Individuals with disabilities. I also teach part-time at C.S.U. Northridge (since 1991), where I teach courses on behavior assessment and positive behavior support, a class on issues related to transition for persons with disabilities, and I supervise teachers in their classrooms while they are completing their credentials.

My "real job", however, is directing a small non-profit agency which provides supported living and individualized day services for 19 persons about 1 hour north of Los Angeles. As a small agency, I have the opportunity to provide more than 20 hours of direct service a week, which ensures that I am still able to learn on the job. My most enlightening experiences have been transitioning a segregated 'behavior management day program' for individuals with autism to community based employment and career services and assisting people to move from large congregate facilities to homes of their own.

I believe that it is important to assist communities to build local strength and advocacy by identifying local family members, self advocates & professionals and providing them with training and resources that they can share with others while they build strength from within. Our TASH conferences have been trying to do this, and I think that we can improve our efforts in this area.

While I spend much of my time at the University focusing on inclusive services for children, I also believe that it is critically important to focus on quality services for adults. Budgets are tight for all services, but federal and state dollars seem to 'shrink' once people turn 22 years old. Post-22 services for adults seem to be relegated under the category of "careprovider" instead of teacher, job-coach, and support staff whose job it is to teach skills as well as to develop natural and typical supports in people's lives. We need to focus on live quality across the continuum, from birth to the sunset of life. Thank you again for this opportunity!"

Photo Not Available

Nancy Ward

"My name is Nancy Ward and I am the Self-Advocacy Coordinator for Oklahoma People First. In this role, I help People First members to see themselves as people and help them gain confidence in learning how to speak for themselves. I get excited about this part of my job because I enjoy being a role model. I like to share with people how it took me five years to gain the confidence in myself to do public speaking. I believe that it is important for people with disabilities to have role models with disabilities because we share many of the same experiences.

Another part of my job is to help People First members learn what their rights are as well as their responsibilities and the consequences of their actions. For example, whenever there is an election in Tulsa, our People First chapter invites the nonpartisan League of Women Voters to come in and explain the ballot so that members can make informed decisions about the candidates and issues.

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2002 TASH Board Election

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As the Self-Advocacy Coordinator, I also support Oklahoma People First on a statewide basis. Each year we have a statewide conference. People First members make all of the decisions about the conference and then I carry out their directions, including making hotel reservations, ordering the food and placing the conference announcements and notices. We also have an annual Legislative Rally Day at the state capitol. At this rally, Oklahoma People First members gather to educate their legislators about disability issues and how they want to be treated. One year we gave our legislators lemons to get our point across about how people with disabilities were sick and tired of having the state take so long to fix people's equipment or to tell us it costs too much to get a new wheelchair, walker, or Liberator.

As part of the National Center on Self-Determination, Oklahoma People First was responsible for the mini-grants for three years. The members made up the committee that gave grants of up to $5,000 to 38 states. They awarded almost $200,000 to self-advocacy organizations across the nation. My role in helping Oklahoma People First with these grants was to help them see the big picture so they could make decisions such as: what criteria they would use, what kind of timeline they should use, and how to find the resources available to answer questions asked by applicants.

On the national level, I was the founding chairperson of Self-Advocates Becoming Empowered (SABE), which is now the national self-advocacy organization. One of my proudest moments was when we realized that we could trust each other because we were working together as a team. While serving as chairperson for SABE, Tia Nelis and myself were the first recipients of the Roland Johnson Speak Out Award. One of the hardest things I had to do was to give up being chairperson of SABE. I realized that if I wanted the national organization to keep becoming the power I wanted it to be, I was going to have to pass on being seen as the chairperson and become a role model in showing how to let go.

Other national positions I have held include being the first self-advocate to be appointed by the president of AAMR to be a liaison on self-advocacy to the national board. In this role, I brought a different perspective to the board to help them understand issues from a consumer's point of view. In this same role, I was also one of the first self-advocates to be appointed to and serve on the board of the ARC US. In 1987, ARC US presented me with their Citizen of the Year Award.

Since 1997, I have missed working on a national level for the benefit of people with disabilities. I believe that I have experiences, contacts and resources on a national level that I could share with TASH and its members. It is for this reason that I would like to be considered for the TASH Board.

And don't forget . . .

Original ballots only are due in the TASH Central Office postmarked by **October 28, 2002!**

Lt. Joseph P. Kennedy Institute
Washington, D.C.

Director of Adult Education and Career Development

Exciting career opportunity for experienced senior-level manager to coordinate and enhance an array of services and supports for both transitioning youth and adults with developmental disabilities to enable them to successfully obtain and retain jobs, and have opportunities for career advancement through customized employment and/or continuing education services and supports.

Qualifications: Master's degree in vocational rehabilitation, special education, or related field required. Minimum five years experience as a manager. Experience with a wide array of services, supports, and models for career development and continuing education for people with developmental disabilities. Must have excellent written communication skills. Experience in grant writing preferred. Salary range: $65,000.00-$75,000.00

To apply submit your resume to:

bstevens@kennedyinstitute.org or fax your resume to (202) 529-3393.

TASH 2002 Election of Five (5)

EXECUTIVE BOARD MEMBERS

Term of Office: 2002-2005

- OFFICIAL BALLOT -

There are five positions for members of the TASH Executive Board to be filled this year. Positions will be filled via ballot by dues-paying TASH members (one each) in accordance with the Association's By-Laws. The Executive Board members-elect will begin their terms at the Annual Board Meeting held in conjunction with the 2002 TASH Conference to be held in December in Boston, Massachusetts.

Ballot Instructions:
You should vote for a total of FIVE nominees. Ballots containing more than five votes are invalid. Please mark your ballot in ink.

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For information about the candidates, please refer to pages 4-10 of this issue of TASH *Connections.*

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TASH: Public Policy in Action

The Survey Results Are In...What do families of students in special education think?

BY KATHY RICHARDSON-BOOKER

On Wednesday, July 10, 2002, Public Agenda, a public opinion research firm, held an open forum to discuss the recently published "*When It's Your Own Child: A Report on Special Education for the Families Who Use It.*"

In April and May of 2002, Public Agenda held telephone interviews with a randomly selected, nationally represented sample of 512 parents of elementary and secondary public school children. The parents were questioned about the special education services they received for their children. Each parent was asked 62 questions for an estimated total interview time of 30 minutes. In addition to the telephone interviews, Public Agenda held parent focus groups, individual interviews with parents and with experts in the field.

TASH recognizes that the report while presenting some useful information, also provided information that is likely to be misunderstood and of limited use because the questions were not written from the perspective that students with disabilities have a right to learn what all other students are expected to learn, to receive specialized instruction and related and supplementary services to enable them to learn in a regular education class setting, and to have any behaviors that interfere with their ability to learn in the most inclusive environment addressed as an education matter.

Overall, however, the results were positive and encouraging! The results indicated that 84% of the parents feel their child's teacher is caring and knowledgeable. Sixty-seven percent of the parents believe that their current school is doing a good or excellent job. The good news does not stop there because parents also indicated their satisfaction with mainstreaming opportunities, academic progress and responsive schools. The report indicates that parents feel like they are a part of the IEP team process, and that their children no longer feel the same degree of stigma that was once associated with special education.

The not so good news from the survey indicated that a majority of parents were less than satisfied with information about how special education works, what it provides and the benefits and rights to which their child is entitled. Sixty-nine percent of the parents agreed with the statement, "Many students wouldn't need to be in special education had they gotten the help in school earlier on." The report also indicated that there is a minority of parents that have serious complaints regarding services and quality of teachers and schools. Sixty-five percent of the parents felt that some children who get special education services really have behavior problems, not learning or physical disabilities.

The most alarming news in the report was the relatively large number of parents surveyed, 31%, who thought "the Federal government had a small role in special education."

During the July forum, the authors of the report took questions from the advocacy and professional community. Audience members raised concerns with the report regarding the relatively small size of the sample, the exclusion of private school or home schooling parents who may have left the school system unsatisfied, and the wording of a few questions. One individual raised the interesting point that if the majority of parents, the primary "consumers" of special education services, were pretty satisfied with services, why were Washington think-tank professionals and policy makers so convinced that IDEA requires reform?

TASH members interested in obtaining a copy of the Public Agenda Parent Survey in PDF format should send an e-mail to Jamie Ruppmann at <jruppmann@tash.org>

NOTE: *We were delighted to have Kathy Richardson-Booker as a summer intern assigned to TASH Government Relations. Kathy is a graduate student enrolled in an Educational Leadership program at The George Washington University in Washington, D.C. She has a Master's Degree in Education with a specialty in Special Education,*

TASH Governmental Relations and Public Policy Director Jamie Ruppmann (left) and Governmental Relations Intern Kathy Richardson-Booker

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TASH Responds to President's Commission on Excellence in Special Education

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Behavior Disorders and Troubled Youth from the University of Maryland. Kathy is a special educator in the Montgomery County, Maryland school system.

TASH Responds to the President's Commission on Excellence in Special Education

We agree that the current system of public education for students with disabilities needs reform. This is especially true for those with significant disabilities. The quality of placements offered to students who require significant services and supports ranges from abysmal to generally good classrooms. Nonetheless, these students are seldom taught academics, especially reading and writing, in any of these settings. TASH members are told that this is because schools don't believe that children and young people with significant developmental disabilities are capable of learning. And the instruction that our students receive in nearly every setting generally has assured that the schools' view will hold true. Special education and IEPs have become in some schools an excuse not to address curriculum at all.

In addition, despite the legal, moral and ethical, not to mention research-backed impetus, the majority of students with significant disabilities continue to be educated apart from their peers without disabilities. Separate is not equal when students are denied the benefit of the full range of opportunities provided to all other students.

We also agree that additional regulations and sanctions are insufficient to change systemic beliefs that students with disabilities are fundamentally incapable learners. Supports, training, communication networks, case examples, demonstrations, model programs and other efforts are required in much larger numbers and greater variety if the system's current inertia is to be effected. The law has advanced light years. Classroom beliefs and practices have inched haltingly and irregularly and slipped in many instances.

TASH members agree that the focus should be on student outcomes and effective practice; unfortunately, districts are not complying with the requirement of the law to provide effective programs in many cases, particularly for students in special classes. We urge that requirements for documenting compliance be kept in place and that the right of due process be kept open and accessible to assure that schools and parents remain accountable to each other.

We are also concerned about the Report's over emphasis on "simplifying" the IEP. We do not support the recommendation that states be allowed to forgo the required documentation in an effort to streamline. We do support identifying the components that should be included in a child's IEP, components such as the identification of short-term educational objectives or benchmarks, central to the creation of a quality educational program for our students. Many of the items included for accountability purposes could then be documented through a separate, efficient data management system.

Generic special education programs are not preparing teachers for the unique and challenging needs they will face in teaching students with significant disabilities. They need to be provided with in-depth knowledge, not simply an overview of special education. Teachers in training must be given rigorous training in reading so that they will acquire strategies to work with students who have unique literacy needs (e.g., those using Assistive and Augmentative communication Devices and students who are deaf-blind).

A critical concern for TASH that has not been clarified in the Report is how this "research base" is systematically delivered to teachers so they can use it to inform their instruction. How are teachers to be guided in thinking about research critically? How are teachers to resolve the questions that researchers continue to argue about? In our view, the largest part of this set of recommendations should address delivery to teachers and schools; systematic and sustained education efforts, support systems, modifications in work load to accommodate learning and reflection, not just planning and delivery.

Thanks to David Koppenhaver, Pam Hunt, June Downing and Kathy Gee for their contribution to this response. For more information, please contact Jamie Ruppmann at (410) 828-8274 x104 or <jruppmann@tash.org>

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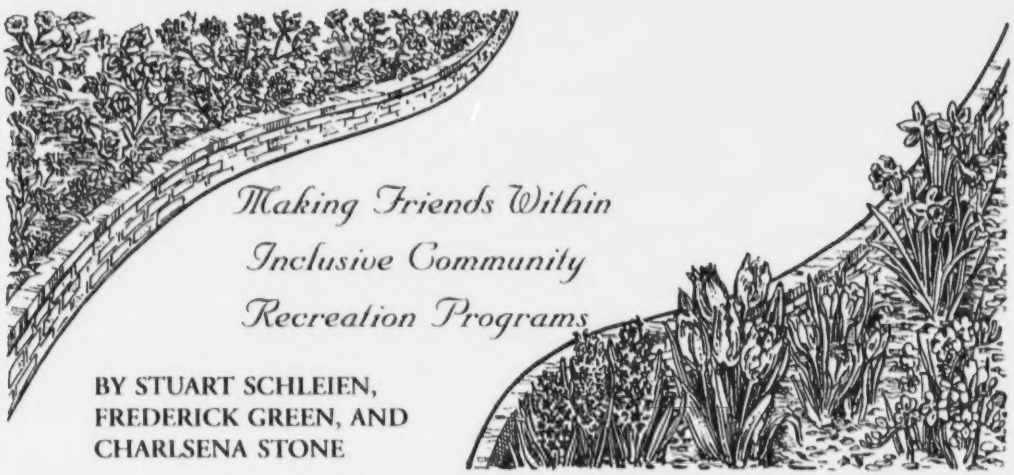

Making Friends Within Inclusive Community Recreation Programs

BY STUART SCHLEIEN, FREDERICK GREEN, AND CHARLSENA STONE

Prior to 1990, it was assumed that participation in recreation activities automatically resulted in healthy social relationships for people with disabilities. The major assumption was that as individuals with disabilities were included in community recreation programs, they would begin to make friends with non-disabled peers as they had been making friends with peers with disabilities in segregated environments. As researchers and practitioners began to take a closer look at friendship and recreation's impact on social relationships, the validity of these assumptions was questioned. Not all recreation experiences facilitated friendship. Likewise, not all social relationships that resulted from participation in inclusive recreation were truly friendships, at least as "friendship" is traditionally defined. These issues had researchers rethinking friendship and the strategies that facilitated its development.

In the past 10 years, efforts to understand this extremely important phenomenon have focused on such issues as defining friendship and related terms (Green & Schleien, 1991; Green, Schleien, Mactavish, & Benepe, 1995; Hutchison, 1990), identifying and creating methods for assessing and measuring friendship (Green & DeCoux, 1994; Schleien, Green, & Heyne, 1993), developing strategies for promoting friendships among people with and without disabilities in inclusive recreation environments (Abery & Fahnestock, 1994; Amado, 1993; Hutchison & McGill, 1998), distinguishing among the types of supports best suited for facilitating meaningful interactions necessary for friendship development (Taylor, Sylvestre, & Botschner, 1998), examining the ethics of efforts to promote social connectedness through volunteer experiences (Anderson, Schleien, & Green, 1993), and establishing the role of therapeutic recreation professionals in the promotion of healthy social lives for individuals with disabilities who are accessing the community (Schleien, Ray, & Green, 1997).

Yet in spite of varying results of these efforts, most agree that friends are a key component of quality of life, and recreation participation is the primary medium for initiating and developing friendships. The purpose of this article is to take a careful look at the phenomena of friendship as it pertains to individuals with disabilities who are participating with non-disabled peers in inclusive recreation environments. We define social inclusion and friendship, and discuss the importance of friendship in relation to inclusion and quality of life. As barriers to friendship are identified, the authors present strategies for promoting friendships between people with and without disabilities as they jointly participate in inclusive community recreation programs.

Social Inclusion

It seems paradoxical, that although recreation seems to be the best medium for meeting people and making friends, it may also be an environment that reinforces social isolation. This occurs when recreation programmers prematurely conclude that efforts to "physically" include individuals into recreation programs will result in social acceptance by peers.

In the 1990's -- the decade following the passage of the Americans with Disabilities Act (ADA) -- the impact of the ADA on the inclusion of people with disabilities into the mainstream of community life appears to parallel the impact that the Civil Rights Act had on the inclusion of people of color. In both cases, the Acts were necessary to ensure the legal rights to access for individuals from traditionally underrepresented minority groups. However, in each case, the right to access did not guarantee social acceptance, a high level of inclusion that cannot be legislated. Consequently, before exploring techniques for promoting social inclusion, it may be necessary to review varying levels of inclusion.

There is no "quick fix" that can be prescribed to enhance friendship development. A program, process, or technique that works with one individual in a particular activity may not be effective in another. Helping an individual realize her personal vision of making friends is therefore likely to require the use of numerous approaches by a variety of key players. Family/care provider involvement in this complex process is crucial.

The concept of inclusion may best be viewed as a continuum that includes three levels of acceptance. In the first level, physical integration, an individual's right to access is recognized and assured. Physical

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integration was the focus of the Architectural Barrier's Act of 1968, which mandated that all buildings receiving federal funds be made accessible to people with disabilities. The ADA expanded the coverage of physical integration to facilities open to the general public regardless of federal funding. Physical exclusion implies intentional or inadvertent practices that prevent individuals with disabilities from entering a facility or joining a program. Sample exclusionary practices include inaccessible facilities and discriminatory eligibility requirements.

The second level of inclusion is functional inclusion. Functional inclusion refers to an individual's ability to function successfully within a given environment. Community recreation programmers practice functional exclusion when they do not make the necessary adaptations to allow individuals with varying abilities to participate in programs or benefit from services. Functional inclusion was partially addressed by Section 504 of the Rehabilitation Act of 1973, which prohibited the denial of benefits under any program or activity receiving federal funding. However, it was the ADA that effectively instigated the functional inclusion of people with disabilities. According to the ADA, programs must provide reasonable accommodations to people with disabilities to ensure equal enjoyment in goods and services (Bullock & Mahon, 1997). Barriers to functional inclusion include lack of individual skills or knowledge, inadequate resources for adapting activities and including people with disabilities, and failure to provide reasonable accommodations. Finally, physical integration is an obvious prerequisite to functional inclusion.

The third and highest level of inclusion is social inclusion. Social inclusion refers to one's ability to gain social acceptance and/or participate in positive interactions with peers during recreation activities. Enjoying activities with friends and/or making new friends would be considered a high level of social inclusion. Because it cannot be legally mandated, true social inclusion is contingent upon internally motivated acceptance by peers. Recreation programmers could, however, promote social inclusion through a combination of internal and external facilitation strategies. The full inclusion of people with disabilities in recreation is not complete until community programs and activities are welcoming, accommodating, and conducive to making friends and sharing experiences.

Because it cannot be legally mandated, true social inclusion is contingent upon internally motivated acceptance by peers.

Friendship

Friendship is a unique, high level social relationship with a myriad of interpretations. Perceptions of friendship will vary among individuals as a result of different social experiences and expectations (Green & Schleien, 1991; Green, Schleien, Mactavish, & Benepe, 1995; Hutchison, 1990). Most people agree, however, that friendship entails certain common attributes that distinguish friendship from acquaintances and other social relationships. According to Howes (1984), friendship is an affective tie between two individuals. Friends choose each other freely (Heyne, Schleien, & McAvoy, 1993), friendship is mutual and reciprocal (Green & Schleien, 1991), and is consistent and enduring (Stainback & Stainback, 1987; Young, 1986). Friendship is often demonstrated behaviorally as noted by shared participation in leisure activities (Green et al., 1995). Recreation appears to be a medium in which friendships develop and flourish. For example, the word friend is partially defined as a person with whom one shares free time and leisure experiences (Green & Schleien, 1991).

Friendship plays an integral role across many of our quality of life domains throughout our lifetime. Rubenstein (1984) noted that friendships allow children to share affection, support, companionship, and assistance. Through play, children teach each other social skills and give each other a sense of belonging. During adolescence, one's need for intimacy and companionship tends to lead to relations with friends who are of similar age, background, and interests (Rubin, 1985). Adolescents spend much of their leisure time with friends, and membership into these social cliques often depends upon an appropriate range of leisure and social skills. Friendship in adulthood appears to build upon a culmination of skills developed during childhood and adolescence. Adult friendship is typically characterized by intellectual stimulation and social interconnectedness (Rubin, 1985), reciprocity in affection (Green & Schleien, 1991), desire and ability to share responsibility for nurturing and maintaining the relationship (Stainback & Stainback, 1987), and ability to share leisure interests with near compatible skill levels (Green et al., 1995).

Friendship and People with Disabilities

As expected, people with and without disabilities have similar needs and desires to develop and maintain friendships. However, for people with disabilities, social networks of friends or intimate relationships are substantially smaller than the social networks of people without disabilities, even though people with disabilities often have sufficient opportunities to interact with peers (Abery & Fahnestock, 1994). According to Amado (1993) and Hayden et al. (1992), people with disabilities often have far fewer relationships than their peers without disabilities. Their relationships are with family members, acquaintances with disabilities, and people who are paid to interact with them. This phenomenon leads one to the conclusion that friendship, and the skills of making and maintaining friends, may somehow be different for people with disabilities. This difference in perceptions of friendship and the responsibilities associated with developing and maintaining friendship can become a significant barrier to inclusion as people with disabilities begin to spend more time in inclusive community environments.

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In inclusive recreation environments - identified earlier as fertile ground for friendship development differing perceptions can become a barrier to friendship. Many people with disabilities define friendship in terms of the frequency of interactions that they have with another individual. On the other hand, non-disabled peers who interact often with people with disabilities may perceive a relationship to be something other than a friendship. Oftentimes, relationships between adults with and without disabilities will lack reciprocity, a key component of friendship. As a result, non-disabled adults will often maintain the relationship only until their sense of obligation has ended (Anderson et al., 1993).

In an attempt to learn more about friendships between adults with and without developmental disabilities, Green and Schleien (1991) found that adults with developmental disabilities living in community residential facilities often do not develop meaningful, reciprocated friendships with non-disabled peers. Rather, they mistakenly perceive staff, family, and other externally motivated or obligated people to be friends. Similar conclusions were reached by Kennedy, Horner, and Newton (1989) in an earlier study of the social interaction patterns of 23 residents of a group home. The authors found that the residents had social contact with an average of 63.5 different people (not including people they lived with and people paid to provide support) over a 30-month period. Yet, they predicted that the residents would most likely not sustain relationships with non-family members. They concluded that individuals with disabilities had difficulty providing the reciprocity and accepting the friendship responsibilities necessary to sustain an authentic friendship relationship.

Although some authors have determined that friendships, although rare, do occur between adults with disabilities and their care providers (Lutfiyya, 1993), often times the continuous process of people entering and exiting their lives leaves one with the false impression that friendship formation has occurred. For the sake of future attempts to assess the existence of relationships, this difference in perspective may be viewed as the result of an inability to distinguish between "friends" and "service providers" (Bullock, 1988).

Children appear to be more accepting of their peers with disabilities as compared to their adult counterparts. As noted by Heyne, Schleien, and McAvoy (1993), this can be explained by the extent to which both children with and without disabilities perceive that they are receiving as much from the relationship as they are giving. Children's relationships, however, lack the stability of adult relationships, which often survive changes to individual lifestyles. As children with and without disabilities grow older together, non-disabled peers may begin to replace friendship-like behavior with supervisory behavior as they begin to perceive differences in skills and abilities. The evolution of the relationship from a horizontal friendship to a vertical social/supervisory relationship parallels relationships typically found between siblings of different ages abilities (Harry, Day, & Quist, 1998).

Friendship and Inclusive Recreation

We believe that segregated programs, where minimal opportunities exist to interact with non-disabled peers, are more beneficial than the complete absence of recreation services altogether. However, a segregated approach does not reflect the legislative, philosophical, and service emphases of the post-ADA era-that community recreation fully and socially include all of its members. Research suggests that individuals with disabilities are happier and quality of life is increased when they are with typical peers than with peers with disabilities only (Logan et al., 1998). Discussions by recreation professionals should not center on whether certain people should be served, or even whether to provide programs in inclusive or segregated settings. Instead, discussions should focus on the most effective ways to ensure that opportunities exist for socially inclusive participation. This section briefly describes three approaches to including people with disabilities in existing recreation programs.

Integration of Existing Recreation Programs Approach

In the "integration of existing recreation programs" approach, an individual who is disabled selects a traditional, age-appropriate recreation program currently existing in the community. A trained inclusion specialist, possibly a Certified Therapeutic Recreation Specialist (CTRS) or other professional with skills to effectively serve people with disabilities, and a recreation program leader identify and attempt to ameliorate the discrepancies between the program's requirements and the individual's capabilities. In this manner, a person who was formerly excluded may at least partially participate in an age-appropriate activity. This approach provides one framework for an inclusive recreation program and may expand participants' social networks in the community at large. Although these efforts appear to be exceptionally time-consuming for staff members at first, they should pay great dividends for all participants. A significant advantage offered by this approach is the exposure to a vast potential network of social relationships.

Reverse Mainstreaming Approach

A second approach to inclusive community recreation is what we refer to as "reverse mainstreaming." In this manner, programs that were originally designed for people with disabilities only are modified to attract and serve non-disabled people, too. This approach-practiced by municipal park and recreation agencies when they invite and recruit individuals from the community to participate in their formerly segregated (for people with disabilities only) summer camps, evening programs, and after-school

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activities - increases interactions between people of varying abilities. Two essential outcomes could occur. First, the addition of non-disabled participants results in a larger participant base, allowing programs to be divided into groups that are based on chronological age. Individuals with disabilities no longer have to participate with others who are many years their junior or senior. Also, people are provided opportunities to interact with and learn from their peers, oftentimes, peers with far greater experiences.

Zero Exclusion Approach

Administrators of recreation agencies are well aware that their programs are in a constant state of change. Last year's fads quickly become this year's memories (the current paintball and "Star Wars" crazes will not last forever). Constantly changing populations with ever-changing interests demand a continuous influx of new, innovative, and exciting programs. This demand for new programs could be the necessary vehicle to promote full social inclusion. The creation of new inclusive programs to meet consumer demand is the basis for this third approach. Therapeutic recreation specialists and recreation program leaders do not plan programs in isolation as is typical within our recreation agencies. Instead, they collaborate to design programs that serve people of varying abilities. Since programs are not targeted for a particular group, the agencies practice the art of nondiscrimination, or full inclusion. They aggressively recruit people of varying abilities to participate in their programs. Unlike the other two approaches, zero exclusion could promote equal status among community members. Rather than creating special programs for certain "types" (labels) of people, these programs are designed with a diverse population in mind.

Strategies for Promoting Friendships in Inclusive Recreation

One may categorize strategies for helping people make friends in two groups: extrinsic and intrinsic. Extrinsic strategies focus on changing the recreation environment to make it more conducive to positive social interaction and friendship development. As noted by Lyons, Sullivan, and Ritvo (1995), as people with disabilities enter the community in greater numbers, it is often the non-disabled peer that needs to become more competent in social relationships with people with disabilities. The assumption is that people with disabilities often become socially isolated because of environmental constraints that prevent others from discovering their positive inherent personal qualities. As facilitators manipulate the environment to increase social opportunities, positive social interactions could result that allow members of the group to discover and share common experiences. These common experiences could serve as the basis for friendship.

It is critical that we begin to take a hard look at current "friendships" that exist between people with and without disabilities and discuss alternative definitions and criteria for judging these relationships. Special attention must be given to planning strategies that increase opportunities to develop and maintain meaningful relationships between people of varying abilities.

Extrinsic strategies for promoting friendship include sociometry (Schleien, Fahnestock, Green, & Rynders, 1990), Circle of Friends (O'Brien, Forest, Snow, & Hasbury, 1989), and cooperative peer companionships (Rynders & Schleien, 1991). Sociometry is a procedure for restructuring large recreation groups into smaller play groups, ensuring isolated members (e.g., individuals with disabilities who have yet to attain social inclusion) the opportunity to interact with those individuals with whom they have the potential to form positive social relationships. Beginning with a sociometric assessment, program leaders identify group members who are isolated and those who are considered popular.

Additionally, existing relationships among members of the group are also identified. This information is used by program leaders to restructure the play groups and identify key individuals who may serve as gatekeepers to the social networks. Isolated individuals are placed in groups with peers with whom there is at least minimal attraction (preferably reciprocated attraction) and away from peers who have expressed rejection. As a result, isolated group members are given the maximum opportunity for positive interactions within their own group. Popular individuals can be recruited to serve as peer companions for those who are isolated. Through acceptance by popular peers, isolated individuals can often overcome initial rejection by social groups, affording them the opportunity to demonstrate their intrinsic qualities to others.

Circle of Friends is an extrinsic strategy designed to assist individuals who may have difficulty entering a group. A small group, or circle of friends, is identified and prepared to assist the target individual to overcome the barriers to group inclusion. The circle of friends is comprised of significant people in the focus person's life. Members typically include family members, friends, and current members of the targeted social group. Program leaders empower the circle of friends to facilitate social inclusion by leading a group discussion focusing on the isolated member's dreams, nightmares, likes, dislikes, strengths, abilities, and needs. The discussion is eventually directed toward barriers to social inclusion, and the support that each member of the group could provide. The circle of friends work with the targeted individual and the new social group to facilitate inclusion in the group's social network.

Cooperative peer companionships supplement the sociometry and Circle of Friends strategies by identifying and preparing a key, same age peer to provide support and facilitate the acceptance of the target member into the group. Peers who are already socially accepted are most desirable. The child with a disability is matched with a

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non-disabled peer companion for participation in activities oriented toward socialization. The non-disabled peer companion is prepared to encourage, prompt, and reinforce cooperative interactions by their peer with a disability. Additionally, by demonstrating acceptance of the child with a disability, peer companions can facilitate social inclusion by breaking down artificial barriers to inclusion.

Intrinsic strategies for promoting friendship are designed to promote change within the individual. As reciprocity is considered a vital criterion for the development and maintenance of friends, an individual's ability to contribute to a relationship is necessary. Environmental changes, while important, may not leave the individual prepared to connect with her social peers. For this reason, extrinsic strategies are most effective when combined with intrinsic ones. Intrinsic strategies are designed to teach age-appropriate, socially valid, recreation and social skills in order to prepare individuals with disabilities to take active roles in establishing and maintaining friendships and other social relationships.

Two intrinsic strategies for developing appropriate social skills within a recreation context include Friendly Action Circles (Vandercook et al., 1994) and leisure skills development (Schleien et al., 1995). Friendly Action Circles is a game for children between kindergarten and 4th grade that allows children to practice friendship behaviors within a group of peers. One at a time, children will select a "friendly action card" that illustrates a desirable social behavior. As children act out the behavior, other members of the group try to guess the behavior being demonstrated. Sample friendship skills taught to younger children (i.e., children from kindergarten to grade 2) include thanking someone, sharing, and offering help. Older children (i.e., children in grades 2-4) are taught these skills as well as more complicated social behaviors, such as giving a compliment, suggesting an activity, and apologizing to someone.

Teaching age-appropriate leisure skills may be the recreation professional's most critical contribution to an individual's social network. By carefully selecting and teaching age-appropriate and popular leisure skills, participants develop a repertoire of skills necessary for making social connections and developing and nurturing relationships. We offer the following guidelines for selecting appropriate activities that may lead to and support friendships.

1. For an isolated individual, having leisure interests that are compatible with peers is essential. The task for the recreation leader prior to instruction is to conduct an inventory of available activities, identifying those activities that are age-appropriate and of interest to the social group being targeted. For example, if John is 8 years old and attends third grade, recreation program leaders will want to identify recreation activities that currently appeal to third graders. It should be from this list of activities that skills are targeted for instruction.

2. Sharing mutual interests is a critical component to positive social interactions. Yet friends will most likely share these interests with others who demonstrate similar skill levels. This allows two people to give and receive equally to the activity (and the relationship), and precludes the need for non-disabled peers to assume "teacher" roles. As skill levels become incompatible, potential friendship relationships often evolve into vertical, supervisory relationships that require non-disabled peers to focus less on mutual satisfaction and more on their obligation to their partner with a disability. To facilitate friendships, program leaders should select activities that are not only popular with the targeted social group, but of high interest to the learner.

3. Common interests and skill levels alone are not sufficient to sustain friendships. Friendships and other significant relationships require that individuals share equal levels of social skills and graces such as reciprocity, communication, and appropriate appearances. For individuals with disabilities who are attempting to make social connections in an inclusive recreation environment, deficits in social skills and graces will result in ostracism - as even the most loyal friend will be concerned about her social position in an extended social network. These concerns can be addressed by including social skills training (e.g., Friendly Action Circles) into the instructional program, and by applying extrinsic strategies that prepare peers to accept and support members of diverse skills.

There is no "quick fix" that can be prescribed to enhance friendship development. A program, process, or technique that works with one individual in a particular activity may not be effective in another. Helping an individual realize her personal vision of making friends is therefore likely to require the use of numerous approaches by a variety of key players. Family/care provider involvement in this complex process is crucial.

Family/Care Provider Involvement

Enhancing friendships and the social inclusion of people with disabilities is not the responsibility of service providers only. Family members must also play important roles. They must be initiators in order to obtain supports needed. However, families want and need more genuine help from professionals and community members who could work with them to address friendship issues and other complex challenges they encounter each day. Partnerships with professionals such as teachers and community service providers are necessary (Turnbull & Ruef, 1997).

According to Schleien, Rynders, Heyne, and Tabourne (1995), if friendships are to

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develop and thrive between individuals of varying abilities, friendship development needs to become a top family priority. For example, if children's friendships are to extend beyond the school day, families need opportunities to meet each other, become acquainted, and mutually support these relationships. Parents can become acquainted with other families in the neighborhood who have same-age children by attending school functions and events at community recreation centers. Parents could also take active roles initiating and scheduling play opportunities for their children by exchanging telephone numbers and addresses, and inviting children into their homes and on community outings. Parents can personally contact other parents by phone or letter, make home visits, and host informal social gatherings.

Turnbull and Ruef (1997) interviewed 17 families of children, youth, and adults with problem behavior and found three different methods that they used to help facilitate friendships. These strategies included having the child participate in inclusive settings so as to have an opportunity to socially interact with peers, paying a companion to spend time with their child, and providing information and skills to peers to help them interact with their child. Some parents indicated that they had asked the child's teacher for a list of "possible friends" to contact outside of school. Families expressed problems knowing how to initiate contact and meet other parents.

For school-age children, school personnel can serve as a common avenue for parents to establish the necessary social connections, through school-sponsored events such as family nights, PTA meetings, open houses, and community education classes. Additionally, parents and school staff could work together to include recreation and friendship goals in Individualized Education Plans (IEPs). Including recreation, friendship, and social interaction goals and objectives in an IEP will ensure that the skills related to these goals will be taught, monitored, and evaluated regularly (Heyne, Schleien, & McAvoy, 1993). Parents should initiate meetings with influential school administrators from local school districts who make policy and programming decisions to advocate for their children's need to make friends and to offer to collaborate in establishing friendship goals.

Families could organize family advocacy groups with similar concerns and a strong commitment to friendship development. Advocacy groups can inform others about the benefits of making friends and strategies useful to ensure friendships are developed and maintained. This group should include a diverse group of families representing different races, ethnicities, and abilities in the community. The group could also include administrators, teachers, parents, educators, community leaders, and other interested relatives and/or citizens. These key players can have an active role in planning and implementing friendship initiatives.

Parents, families, and/or family advocacy groups could consider making presentations to related groups such as parents groups, local civic groups, and local and state chapters of the Arc about potential benefits of making friends for their children. Presentations could focus on what friendship is, why friends are important, successful friendship development strategies, and goals for the future. Hamre-Nietupski et al. (1988) identified the use of visual aides such as slides and videotape of students with disabilities interacting with their non-disabled peers as effective strategies to generate community awareness and support.

A Final Word on Friendships and Recreation: Challenges Ahead

The social inclusion of individuals with disabilities in community recreation has become an accepted focus of recreation providers. Practitioners and care providers alike have discovered that participation in inclusive recreation programs provides opportunities to acquire a variety of functional recreation and social skills.

However, in spite of these efforts, the social networks of children and adults with disabilities continue to look very different from the networks of their non-disabled peers. Individuals with disabilities have far fewer relationships, and those relationships are typically restricted to family members, other people with disabilities, and paid staff. Parents/care providers, recreation professionals, teachers, and community members, as one of their highest programmatic priorities, must begin to help develop, and then promote the maintenance of relationships. It is no longer adequate to consider, for example, the 5-week, integrated summer camp a success, if a camper who is disabled makes a "friend" or two during camp, but does not continue to enjoy those relationships during the following school year. The challenge is to create collaborative linkages among all stakeholders - people with disabilities and their families, friends, teachers, administrators, local citizens, and neighbors - to embrace the complexity of friendship development and to devise new supports and services to translate this vision into reality.

It is critical that we begin to take a hard look at current "friendships" that exist between people with and without disabilities and discuss alternative definitions and criteria for judging these relationships. Special attention must be given to planning strategies that increase opportunities to develop and maintain meaningful relationships between people of varying abilities. If these efforts are not successful, a large segment of our population will most likely remain stigmatized and socially isolated from their non-disabled peers.

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Thoughts From the Kids Next Door or Did We Really Need to be Told This?
Play is the first place a person with a disability can be included[1]

BY CARSON PROO, PHILLIP CONTRERAS, VERONICA MOORE, ERIN JANNEY, AND LIZ KEEFE

The purpose of this article originally was to examine the literature on inclusive recreational opportunities while including perspectives of individuals with disabilities. The co-authors of this article all have an interest in integrated community recreational and educational experiences for all people, including those with disabilities.

The first two authors, Carson Proo and Phillip Contreras, are young men who have disabilities. The second two authors, Veronica Moore and Erin Janney, are doctoral students in the Special Education Program at the University of New Mexico (UNM). The final author, Liz Keefe, is a faculty member in Special Education at UNM. We came to this task from a different base of experiences and offered different voices.

As the senior author in charge of putting the final piece together, I (Liz Keefe) listened to each narrative and examined the existing literature base. I struggled more and more with how to write this seemingly simple article on inclusive recreational opportunities. Two major quandaries surfaced during the mixing of the narratives and the research literature.

First, I believed it was not enough for the voices of people with disabilities to be included solely as narrative support for the professional literature. The first two authors are young people who were excited by the opportunity to publish an article on what they do for fun. These authors' experiences, like those of Pauley (1998), needed to be heard and valued on their own merits rather than being filtered through a researcher's theoretical lens.

Second, the research on this topic merely substantiated information that should have been obvious to the kids next door and anyone who truly believes that all people belong. The literature on the participation of people with disabilities in structured and unstructured leisure activities outside of the school setting was limited and of limited use. The research that was available was most likely well-intentioned, but the results were not earth-shattering for those with disabilities and their advocates. It told us what people with disabilities already knew and what should have been self-evident. I decided it was not appropriate to base the paper around the existing literature and then substantiate this research with the voices of people with disabilities. Instead, in collaboration with the other authors, it was decided to make the narratives the central focus of the article. The research then seemed to state the obvious and led me to ask: "Why did we have to be told this?"

<u>One Kid Next Door: Carson's Story</u>

"My name is Carson. I am in the 10th grade at Amy Biehl High School in Albuquerque, New Mexico. I go to school every day. I go to my classes by myself. I do the vending machine and count the money from it. And the lunch money, too. In math I am working on addition and perimeter. In science I made compost. It stinks, too. In health I learn about sex education. And I learn about how I can go out in the community to serve my life out of school. I go to the dance at night. I stayed up until midnight with the girls and guys. I have so much fun there. I play basketball with boys and girls, we have games.

What I do after school, I go to Hollywood to get a movie and a coke. I go to the park to have fun there. I play my Nintendo 64 and I play my Game Boy alot. I teach art to children, I show them how to shade in pictures and I have fun teaching them. I do my mandolin, Special Olympics, ride my bike around the park. I love to listen to music, I make tile tables, and I play with my legos. I go to the Special Olympics once a week and I practice a lot. I do rings, p-bars and floor practice and I work with a team. I always write more stories. I always go to the gym and I am always playing my Game Boy. And I always play on my computer a lot. I have sleepovers. My best friend is Carter.

I started karate when I was about 10 years old. I am getting my Brown Belt in karate. I listen to my sensei by doing my new katas and making my sensei happy. My instructor's name is Sensei Randy. He is my karate teacher. My dojo name is Shotokan New Mexico Karate. Karate makes me strong and healthy. Martial arts are many things. They are ways to protect myself if some one attacks me. And they are ways to improve my body and mind. I have seen actors use martial arts in the movies. Martial arts build strong bodies

Carson (foreground) practices his moves in his karate class.

[1]Carter, 1999, p.3

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and strong minds. I teach children karate.

My dad and momma and I go to the Telluride Bluegrass Festival. I ride my bike to the grounds. There are lots of bike racks. I go to get lunch there, and I listen to bluegrass music. I sometimes bring water guns to the grounds. I have great time there. On Saturday night I listen to Sam Bush there.

My dad and my mom and I also go camping. We unload our things like our tent, cooler, and stove. I go hiking down to the lake. I hear birds. I go swimming in the summer time. I have great friends there, and I always have a great time there."

The Kid Next Door, All Grown Up: Erin's Story

"I attended elementary school with Robert, who used a wheelchair and other adaptive equipment. My classmates and I helped Robert and other students with disabilities. I remember that Robert was just one of the class. He went out to recess, played, had friends, and did whatever the other students did. I believe this experience had a major influence on my openness to teach in inclusive settings. As a doctoral student, I did my first major research review on inclusive recreation for children with disabilities. I am very passionate about this topic, which is why Liz asked me to co-author this article."

Another Kid Next Door: Phillip's Story

"My name is Phillip Contreras. I am16 years old. I attend Cibola High School in Albuquerque, New Mexico. I participate in a Community Based Instruction Program. We call it CBI. We go out in the community. We go bowling, to the movies, shopping, to the zoo, museums, and to restaurants.

At school I ride an exercise bike during physical therapy. I also use weights. I have my own computer in the classroom. It has an art program on it. I'm part of the yearbook staff. In yearbook class I watch how they organize the yearbook. I'm helping create captions for the pictures.

I have a lot of friends at school. My friends watched me win Valentine King at the Valentine Dance in middle school. I get along with my friends well.

After school, I go to a community center. At the center I ride around in my power wheelchair. Sometimes I do arts and crafts. At the community center I hang out with the rec leaders. I talk about music and basketball and what I did over the weekend. I ask them if they saw the Cowboys game (I'm a Dallas Cowboys fan).

At home I play video games on my Play Station 2. I also watch sports such as racing, football, basketball, the X-games and wrestling. I used to attend a therapeutic horsemanship program called 'Cloud Dancers.' It was in this program that they taught me how to horse trot and how to ride by lying down on the horse. By lying down on the horse it helped me to stretch my back out. I also was in Special Olympics and wheelchair soccer.

I like to go to the movies, New Mexico Lobo games, and to see monster trucks rallies. I go to the Albuquerque International Balloon Fiesta and the New Mexico State Fair every year with my family. I would like to be able to go places with my friends, like to basketball and football games."

The Teacher in the Next Classroom: Veronica's Story

"I currently teach in a high school where students with severe disabilities have recently been included into yearbook class for the first time. From talking to some of the students I discovered that these students don't question why students with disabilities are in their class. Instead they ask where they have been in the past. I remember when Jerome, one of the most popular students in the school, in talking about his classmate with a disability said: 'I'm looking forward to seeing him, he's just like a friend now. I'm learning a lot from him, we sat down and really chatted and actually were communicating.' I am also a doctoral student who has been reviewing the research on the inclusion of students with disabilities in extra-curricular activities and community programs."

Being in the community does not make one part of the community (Sable, 1995, p. 214)

The Research Story

These narratives illustrate several themes about the importance of inclusion in structured and unstructured recreational activities. These themes are well supported by the literature. A brief summary of the available research findings indicates the following:

- Participation in recreational, leisure, and sports activities is very important to the self-concept of individuals with disabilities (e.g. Cordova et al, 1991).

- Participating in recreational activities leads to feelings of belonging, acceptance, and competence (Mahon, Mactavish, & Bockstael).

- People with disabilities participate in recreational activities for the same reasons as people without disabilities (e.g. Page et al., 2001).

- Physical activity leads to more social integration and social integration legitimizes a person's social identity (Blinde & McCallister, 1998; Taub & Greer, 2000).

- Friendship is an important factor that contributes to a sense of belonging at all ages (Mactavish, Mahon, & Lutfiyya, 2000).

- School-age peers, particularly girls, are very accepting of children with disabilities who want to participate in recreational activities (e.g. Block & Malloy, 1998). However, physical integration alone is not enough to increase acceptance, there must be opportunities for interaction between

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children with and without disabilities (e.g. Sable, 1995).

❖ Parents of children with and without disabilities view participation in recreational activities positively (e.g. Block & Malloy, 1998; Megginson, Nakaumura, & Furst, 1997).

❖ If siblings and/or parents are involved in the community, then the children with disabilities were included also (Gallagher, Floyd, & Stafford, 2000).

❖ Coaches/instructors for the most part have a positive attitude when it comes to including an individual with a disability in recreational activities. Not surprisingly, coaches were more likely to feel positive about the experience if they had previous experience or training on inclusive practices (e.g. Bishop, Rizzo, & Silva, 1999; Ledman & Thompson, 1991). Coaches may not be as favorable toward including students they perceive as having severe disabilities (Conaster, Block, & Lepore, 2000).

Did We Really Have To Be Told This?

However, we must return to the question: has this research revealed anything that we did not already know? It reported that opportunities to participate in recreational activities, friendship, and social integration are very important to all people. The research also tells us that people without disabilities will be accepting of inclusive recreational activities if they have an opportunity to experience such activities. For professionals, experience and knowledge about how to include all children are critical. The research as a whole indicates that increased exposure to and contact with people with disabilities does lead to positive views (e.g. Krajewsi & Hyde, 2000).

Students in schools have reported favorable, even transformational changes in their attitudes towards students with disabilities from their experiences in inclusive school environments (e.g. Fisher, 1999). It seems reasonable that these same experiences could occur in community recreational settings if the inclusive opportunities are provided and supported. Perhaps if we listen more closely to the kids next door, we won't need to be told this again. It is time for us not just to listen to these young people but to let them participate as partners as we struggle with the issues of how best to achieve equity, quality, and social justice for all people.

About the authors:
Carson Proo is in the 10th grade at Amy Biehl Charter School in Albuquerque, New Mexico. For the first time in his educational career, Carson is fully included in general education and all aspects of the school. Phillip Contreras is in 11th grade at Cibola High School. Phillip is in a Community Based Instruction Program and currently is only included in general education for two periods a day. Veronica Moore, M.A., is a doctoral student at the Univeristy of New Mexico and a teacher at Cibola High School. Erin Janney, M.A., is a doctoral student at the University of New Mexico. Liz Keefe, Ph.D., is an Assistant Professor of Special Education at the University of Mexico. Dr. Keefe has been active in TASH since 1991, and is a leader in the SunTASH (New Mexico TASH) local chapter. Dr. Keefe has authored two articles published in Research and Practice for Persons with Severe Disabilities and presented numerous times at TASH conferences.

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The conference portion of the show is comprised of over 200 multi-disciplinary seminars, produced by the EP Foundation for Education, Inc., along with collaboration on a 50 session Employment Symposium and Pavilion, sponsored by the Florida Division of Vocational Rehabilitation Services and McDonald's Corporation.

CME and CEU accreditation is being offered through the University of Pittsburgh School of Medicine. CEU accreditation has been awarded for nurses (12 hrs), athletic trainers (16 hrs) & social workers (16 hrs), speech-language pathologists (1.2 hrs), OB/GYNs (10 cognate hrs) and for educators (1.3 hrs) through the Council for Exceptional Children. CEUs for OTs, PTs, recreational therapists & family practitioners are pending.

In addition, a special Assistive Technology Learning Center will be added to the educational program, sponsored by the Florida Alliance for Assistive Services and Technology, Inc. Attendees will learn about the latest products and services from more than 250 exhibitors representing pharmaceutical, home medical equipment, mobility, automotive, furniture, personal care & many other industries. And, back by popular demand ... the Sports & Recreation Activity Center, produced by America's Athletes with Disabilities, Inc. For more information or to receive a free conference brochure, visit: www.wcdexpo.com, email: wcdinfo@wcdexpo.com, or call: 877-923-3976.

In Memoriam
Justin Dart, August 29, 1930 - June 22, 2002

"You have the power and therefore the responsibility to revolutionize your life and the lives of others for the better. You don't need any title, permission or membership card. Act today! Join, lead the revolution of empowerment."
—Justin Dart

On Friday, July 26, 2002, the 12th anniversary of the Americans with Disabilities Act (ADA), people with disabilities, leaders in the disability rights movement, ordinary citizens, and many others joined with a former president of the United States, congressional representatives, and cabinet officials to honor the life and the work of the man many have described as the father of the Americans with Disabilities Act. The afternoon's proceedings at the New York Avenue Presbyterian Church in Washington, D.C. were broadcast live on C-SPAN. It was a tribute befitting a national leader who had dedicated over 50 years of his life to improving and empowering the lives of countless others.

TASH joins with the hundreds of organizations and thousands of individuals who have lent their collective voices and hearts to paying tribute to the legacy of Justin Dart. We offer here a few memories and reflections of those who had the privilege of meeting, working alongside, and knowing this true American patriot.

I met Mr. Dart in 1988 at one of the countless meetings he organized around the country to generate grassroots support for a proposed law he was championing, The Americans With Disabilities Act. I had followed his career for some years and I had been excited by his courage and visionary leadership. But when I first heard him speak, I was instantly transfixed by the power and eloquence of his oratory. I realized that I was in the presence of a historic figure - with a unifying message and a spellbinding style. He taught and urged collective action. Afterwards, I introduced myself. And I asked Mr. Dart if he would possibly consider having his oratory recorded and interwoven with disability rights music. He said that he would consider such a project.

Eleven years later I was collaborating with TASH concerning an album commemorating the organization's 25th anniversary. I suggested asking Mr. Dart if he would allow a recording of his elocution for the project. In September 1999, I set up my equipment to record him reading a page of double spaced text — four excerpts from the keynote address he had delivered in 1996 at the TASH Conference. We were recording in Mr. Dart's home office where he lay in a hospital bed, weakened by two heart attacks twenty months before. He was wearing a crisp white shirt, power tie and dress slacks. Mr. Dart quietly read the text twice through. We both knew the recording was lacking. Mrs. Dart raised his bed so that he was sitting fully upright. Mr. Dart asked her for some orange sections. He ate the orange and told how his father, once a football player, would eat oranges at the half to gain strength for the conclusion of the game.

He cleared his throat and began to read. He spoke with full, majestic, electric power. As I packed my gear, I asked him about his mastery of oration. Mr. Dart reflected how he had worked on his public speaking for years, including repeated listenings to the recorded speeches of FDR and Teddy Roosevelt. I am fortunate to have those four recorded segments of Mr. Dart's stirring words on the album created to celebrate TASH'S silver anniversary. Thank you Mr. Dart for your fearless, loving and tireless leadership and your living words. Solidarity forever.

Jeff Moyer

"I AM WITH YOU. I LOVE YOU. LEAD ON."

HEAR JUSTIN'S VOICE CONTINUING TO LEAD US TOWARD A FUTURE OF JUSTICE.

In 1996 Justin Dart was the keynote speaker at TASH's annual conference in Chicago. For many who were present that day his ringing voice, the voice Lucy Gwin of *Mouth Magazine* calls an "Old Testament voice," continued to echo long after the conference was over.

In January 2000 Jeff Moyer of Music From the Heart, an independent publisher of advocacy-oriented music, joined with TASH and released a CD entitled, *"See How Far We've Come,"* a retrospective of music capturing the last quarter century of progress in the disability rights movement. This debut collection incorporates the stirring and memorable oratory of Justin Dart with the songs and poetry of Jeff Moyer, a leading songwriter, musician, and disability rights activist.

The album teaches, entertains, inspires, uplifts and challenges. The music, combined with the stirring messages of Justin Dart, calls on each of us to continue our work toward equity, diversity and inclusion.

Hear Justin's inspiring words again. Copies in both CD and cassette format are available through TASH, 410-828-8274, ext. 104, and from Music From the Heart (440) 442-2779 or (888) 323-0626 or www.jeffmoyer.com.

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In Memoriam: Justin Dart
August 29, 1930 - June 22, 2002

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Justin and Matthew Dotson

Leaders

There are so many of the great disability leaders who left us behind on this earth to carry on with their work. They started, but they did not finish...who will finish their work? The answer is we have to!!

Can we really fill their shoes (or their boots)? I am up to the challenge, are you? I think if we all work together as a team we just might be able to do the job. From California to New York and back again, we all have the same kind of issues to work on, so we need to get to work and finish a job that our leaders before us started. We might want to mourn for the leaders, but hey we need to get busy and fight the battle.

I wonder whether our leaders who left us to carry on are looking down on us smiling, because they know they left the fight in good hands (or whatever body parts you can use). On the other hand, they might be sad because we are not fighting hard enough. So I say we can take time out to remember them, but not too much time, because we need to get busy and fight. We still have a lot to do...and they are counting on us to finish their work

Liz Obermayer

I had hoped Justin would include a very clear reference to the People First effort to make communication accessible to people who do not read in his keynote address for the International People First Conference in Anchorage, Alaska in 1998.

As I recall, he had a heart attack around the time of the conference and was unable to do the keynote address. I spoke with his wife, Yoshiko, about our connection with Tokyo People First and how helpful it was for us. We talked about how adjustments to understand cultural difference are very much like understanding reasonable accommodation. I explained how including different cultures and having members learn different languages helped the whole process of understanding difference just by doing the practical things we needed to do.

I think Justin had a keen appreciation for the process of understanding, how this leads to appreciating difference and how this can lead to loving people because of their difference. He was a man who was not afraid to say he had a great love for his brothers and sisters with disabilities.

I vividly remember seeing Ashika Teramoto on a computer screen at a gathering in Ashland, Massachusetts. Twenty people in the self advocacy office of Speak Out America in Ashland were crowded around a one inch square picture of a Japanese man attending a conference in Anchorage. I felt like The People First movement had done the equivalent of landing a man on the moon! Justin wasn't there, but everything about Justin was there, anyway. We had him there with us, in spirit. He gave us something that can never be taken away, not even by his death.

The irony of his heart condition limiting his specific advocacy during that time is something I think about a lot. Justin was not dead, but death was giving him a serious run for his money. Because of this, we needed to pick up the ball without his help. In retrospect, I think that was a perfect tribute to a brave leader who needed to pay attention to another front. We picked up the ball and did everything we planned to do. We will always do that.

Lead on! is not a hollow slogan. It is a bold and respectful call to duty. It is our marching order. It is his legacy and it belongs to every single one of us exactly the same way.

What is the reasonable accommodation for death? In the case of a man like Justin Dart that question actually has an answer: Lead On!

Don OCallaghan

It is sad that we lost Justin. What a wonderful man. To fight for all; he believed in everyone; he will be missed by all. But never forgotten. All of his work is in all of us to keep the movement going. He believed in the people and never let anyone tell him different. He was a person who believed in SABE (Self Advocates Becoming Empowered) and all of the board. He was always there when we needed him. He gave to the Campaign for Freedom, and he spoke at different places and kept up the fight no matter what.

Thank you to his family for letting us have him and sharing him with everyone. To all his family he was a wonderful man and will live in my heart forever. Please think of something to do at the TASH conference for SABE that shows we are keeping the movement going! Thank you, Justin. We will always love you!

Tia Nelis

Justin and Yoshiko Dart

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In Memoriam: Justin Dart
August 29, 1930 - June 22, 2002

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An Appreciation of Justin W. Dart, Jr.

For every social problem there is a leader who is called to action. For those of us in the disability community, Justin W. Dart, Jr., was that leader for civil rights and social justice. Mr. Dart, 71, passed away on June 22 and people across the nation are in the process of remembering and celebrating his life of leadership and accomplishment.

Mr. Dart, who characteristically wore cowboy boots and hat, has been called "The Father of the Americans with Disability Act," and "The Godfather of the Disability Rights Movement." Senator Tom Harkin, Iowa Democrat, called Mr. Dart, "The Abraham Lincoln of the disability community." His leadership was instrumental for passage of the ADA in 1990. His advocacy for people with disabilities spanned many years and was filled with triumphs and some disappointments.

Some have suggested that Mr. Dart was a Democrat-turned-Republican-turned Democrat, but his politics are not as important as his leadership. Justin Dart, Sr. was a political conservative and an early supporter of Ronald Reagan. Perhaps, as a result of his father's political ties, the younger Mr. Dart was appointed as Commissioner of Rehabilitation Services in the Department of Education in 1986. He didn't last very long in that position because he grew tired of the government's "paternalistic attitudes about disability." He resigned in 1987.

Perhaps Mr. Dart was discouraged by his government experience. Indeed, the government's "paternalistic attitudes about disability" are a longstanding injustice that has been well documented. I know what I am talking about because, like Mr. Dart, I experienced it firsthand.

In a way, I am a recipient of Mr. Dart's bold leadership as well as his sweat, tears, triumphs and disappointments. Mr. Dart returned to government in 1989 to head the president's Committee on Employment of People with Disabilities. In this position, Mr. Dart urged business leaders to comply with civil rights legislation for people with disabilites. Many business leaders did so; others insisted on expensive legal battles they ultimately lost either in court or in public opinion. Mr. Dart left the Committee in 1993.

I first learned of Mr. Dart in Joe Shapiro's 1992 book, "*No Pity.*" During my dispute with the government, I attended many events where Mr. Dart and his wife were in attendance. One time, I meet Mr. and Mrs. Dart at an Arlington, Virginia, fundraiser for Virginia Lieutenant Governor candidate John Hager, also someone who used a wheelchair. I jokingly asked Mr. Dart why a Democrat like him would be supporting Mr. Hager, a Republican. He said he didn't see any problems in supporting Mr. Hager and that he was proud to have been a Republican for Bill Clinton in 1992. I supposed he wanted me to know that he had not totally abandoned the Republican Party. Although we disagreed on Clinton, I admired his dedication to his work.

There were many other events, rallies, and marches where I had the opportunity to see Mr. Dart in action. He never disappointed anyone. He was a born leader. I am proud that I had a chance to see the leadership that earned him the Presidential Medal of Freedom, the nation's highest civilian honor, in 1998. He well deserved the medal, which he characteristically shared with disabled friends.

I last saw Mr. Dart at the American Association of People with Disabilities (AAPD) Leadership Gala in February. It was a cold evening and Mr. Dart was wrapped in a wool blanket that covered his legs and chest. There were hundreds of people at the event, and Mr. Dart arrived just before the event began, perhaps to avoid the crowd. I recall that he seemed tired yet interested in the people who stopped to chat with him. During the event, the master of ceremonies mentioned that Justin was in attendance and the audience gave its rousing applause. Justin realized the appreciation, admiration, and, yes, the love of the audience. As if there had been any doubt.

Many words will be written about Justin W. Dart, Jr., and let not the least of them be that he was a good and honorable man who made a difference in the lives of many. He saw a better society for people with disabilities and worked hard to get us there. We must continue to work to make Mr. Dart's vision a reality. Although he is gone we must never forget what he meant for our movement. Yes, he was a good and honorable man."

James Patterson

"I had been told at one time that TASH was an organization of extremists. I thank God for the extremists of TASH. I am proud to be a member.

You of TASH have provided courageous cutting-edge leadership, magnificent initiatives that have given millions of Americans with disabilities the potential to move from institutions, poverty and welfare to community and productivity.

From independent living, IDEA, and deinstitutionalization, to supported employment, supported living, assistive technology, self-advocacy and the historic ADA, you have led the way. Your passionate, principled creativity has enlarged the lives of millions like me. Lead on!"

Justin Dart, Father of the American Movement for Disability Rights

TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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VOLUME 28 • ISSUE NUMBER 9/10 • SEPTEMBER/OCTOBER 2002

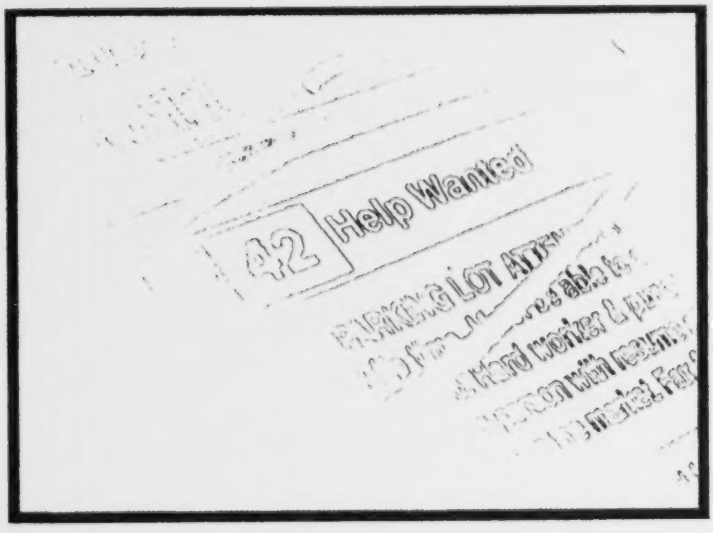
TASH CONNECTIONS

Equity, Opportunity and Inclusion for People with Disabilities since 1975

Inside This Issue

- Using Personal Networks to Achieve Goals
- Increasing Consumer Choice Using SSA Work Incentives
- Growing Jobs in Rural Communities
- Employment: From Competitive to Customized

Customizing Employment Opportunities for People with Disabilities



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TASH Connections is available on audiocassette, in large print, and in Braille for people whose disabilities make these alternative formats preferable. Call (410) 828-8274 ext. 102 to request an alternative format.

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Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. **TASH** actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: **TASH**, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

TASH MISSION

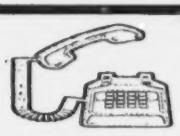
TASH supports the inclusion and full participation of children and adults with disabilities in all aspects of their communities as determined by personalized visions of quality of life.

TASH's focus is on those people with disabilities who:

- Are most at risk for being excluded from the mainstream of society
- Are perceived by traditional service systems as being most challenging;
- Are most likely to have their rights abridged;
- Are most likely to be at risk for living, working, playing, and/or learning in segregated environments;
- Are least likely to have the tools and opportunities necessary to advocate on their own behalf;
- Historically have been labeled as having severe disabilities; and,
- Are most likely to need on-going, individualized supports in order to participate in inclusive communities and enjoy a quality of life similar to that available to all citizens.

TASH accomplishes this through:

- Creating opportunities for collaboration among families, self-advocates, professionals, policymakers and other advocates;
- Advocating for equity, opportunities, social justice, and rights;
- Disseminating knowledge and information;
- Supporting excellence in research that translates to excellence in practice;
- Promoting individualized, quality supports;
- Working toward the elimination of institutions, other congregate living settings, segregated schools/classrooms, sheltered work environments, and other segregated services and toward replacing these with quality, individualized, inclusive supports;
- Supporting legislation, litigation and public policy consistent with **TASH**'s mission; and,
- Promoting communities in which no one is segregated and everyone belongs.



WHOM DO I CONTACT?

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Meetings and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 2002 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
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From the Executive Director

BY NANCY WEISS

Another Tragedy ...

At age nine Matthew Goodman went to live at the Haddonfield, New Jersey campus of Bancroft, a residential school for children with autism. There his mother, Janice Roach, family believed that Matthew would receive a good education and appropriate therapy. He lived in an apartment on the Bancroft campus for four years. He had some behavior problems, but a former teacher at Bancroft described Matthew as funny, social, and easily redirected when he got upset. He loved school and social events. He played games, teased, made up stories, watched videos and was always ready to go for a walk.

During the summer of 2000 Matthew developed a staph infection. He needed intravenous (IV) antibiotics. He was hospitalized in a community hospital and restrained for two months so that he wouldn't pull out the IV. He was terribly upset and begged for the restraints to be removed. When the hospital staff did remove the restraints for short periods he was so distraught he would pick at his skin and tear at his ear. When he returned to Bancroft, the staff there asked his parents for permission to put him in their medical unit for just two weeks and to put arm splints on him during this time so that he wouldn't pull at his ear to allow his ear to heal.

The restraints were never eliminated. Matthew would beg to have them off, but staff told his mother that they thought he would injure himself if they took them off. They added medication to sedate him, then more medication, then leg restraints and, finally, a helmet with a face guard. His mother was frantic. Against the protests of his parents, Matthew was made to wear these restraints almost all of the time. They came off only after he was asleep. Staff told his mother that the restraints needed to be on all of the time because if they were to take the restraints on and off, Matthew might perceive them as a punishment.

Matthew in restraints at Bancroft.

Matthew was no longer taken to school, saw no friends, enjoyed no recreation, went on no more walks, and was offered no activities or programming. This was the readiness model taken to absurdity. It seemed as if Bancroft had no way of viewing Matthew's behavior as anything other than a response internal to who he was; no ability to view his behavior as a response to what little life he was offered. Until Matthew demonstrated that he no longer needed the restraints, they would stay on. And as long as they stayed on, the behaviors for which they were prescribed could do nothing but get worse.

Matthew's parents hired consultants who understood the relationship between behavior and environment. They came to Bancroft and spent time with Matthew. They recommended positive behavioral interventions that they were confident would be effective. All of them were clear that the restraints needed to come off. No changes were made to Matthew's services in response to these recommendations. The State of Pennsylvania was paying Bancroft $350,000 a year and for this almost $1,000/day, Matthew was kept drugged and restrained on the floor for months on end.

This independent, funny, charming kid now had to be fed and toileted. The mother of another resident on the same unit said that she saw Matthew at least weekly for six months and was shocked to learn later that he was ambulatory. She never saw him walk or speak. She said, "on those rare occasions when he was awake, Matt would reach out his hand to me and try to talk as though pleading for help." She said that she couldn't get the image out of her mind of the affectionate, outgoing boy Matthew must once have been.

Matthew's mother visited him regularly. Often she was told that they had added another medication or upped the dosage of one he was on. Eventually, he spent his days lying on the floor, drugged and unresponsive. He couldn't lift his head. His mother was on the phone for hours every day desperately trying to find another place Matthew could go and begging with the funding agencies in Pennsylvania to authorize funds for a different kind of service. She told everyone she spoke with that Matthew was dying; that the restraints were going to kill him. She was dismissed as an overly emotional mother. Once people heard that this was a kid who was in restraints all day, no program wanted to take him.

Finally, Matthew's mother found a program willing to take him in Florida. The people from the Florida program who visited him were horrified at what they saw and assured his mother that there would be no restraints in their program. Matthew's mother arranged private air transportation through a charitable organization and with relief, scheduled his departure from Bancroft for just a few days later.

On Sunday, February 3rd of this year, Matthew's mother went to Bancroft to tell Matthew that it wouldn't be long now. She had found a place where he could go. He would be leaving on Thursday, just four days later. Matthew's mother laid down next to Matthew on the floor with her face next to

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ANOTHER TRAGEDY. . .

Continued from page 3

his. She held his face, caged in his helmet, and promised him that life would be better and the restraints that he hated so much would soon be a thing of the past. She urged him to hang in there for just a few more days.

But Matthew didn't get the days he needed. Just three days later, the day before Matthew was to leave Bancroft, Matthew's mother got a call from a nurse on the unit at Bancroft who said, "I'm sorry to have to tell you this, but we can't find any vital signs." His mother asked what hospital they were at, ready to run out the door and meet them. The nurse told her that they were not at a hospital. Matthew's mother said to call her right away from whatever hospital he was taken to -- she would meet them there. She waited for a call. The Bancroft staff never called 911. They took time to pack an overnight bag with clothes for Matthew. Staff carried him to the agency van. They then drove over 50 miles, past 5 other hospitals with emergency rooms, to an out-of-state hospital in Philadelphia. When they arrived at the hospital Matthew was still alive but he was in shock. He was unconscious but still wearing the ever-present restraints. He died the next day from sepsis (a toxic condition resulting from the spread of bacteria), pneumonia and acute respiratory distress. He had been in restraints for sixteen months.

The state investigation found numerous violations related to Bancroft's failure to follow Matthew's behavior plan. It was also found that Matthew's psychologist who prescribed the restraints was, in fact, not licensed or certified as a psychologist. He was a psychologist in title only. The school was fined $100,000, less than a third of what they had been paid to care for Matthew over the past year, and they continue to operate. They were just granted a full license to continue operations.

Restraints and seclusion are not treatment. Rather, they represent the failure of effective treatment. While it is sometimes necessary to physically intervene briefly when someone is at imminent risk of hurting him/herself or others, when physical intervention is needed the very next questions we should be asking are:

- What is frustrating this person?
- What would he change about his life?
- Does she have a life that is meaningful to her?
- Can she tell us what she wants or needs, and are we listening?

Dangerous or disruptive behavior can be reduced by making people's lives better -- by enhancing, rather than sacrificing self-esteem, relationships with others, and human dignity. The use of seclusion and restraint results in psychological harm, diminished self-image, loss of dignity, and too often, serious injury or death. Post-traumatic stress disorder is increasingly being diagnosed among persons who have been subjected to the systematic use of seclusion and restraint. These procedures are used far too often for the purposes of control, as a punishment, in place of quality programming, as a substitute for adequate skilled staff, or to take the place of a life that's worth living. We fool ourselves into believing that such procedures are a necessary or conscionable part of treatment.

There are no federal regulations or legislation preventing the kind of abuse Matthew suffered. The Federal government has no reporting requirements for deaths or injuries while in seclusion or restraint for public or private school programs, camps, or agencies serving adults with disabilities.

Matthew's mother and other advocates are working to pass a law in New Jersey that would make restraint, other than brief physical intervention for safety, illegal. She is fighting to assure that Matthew's death was not in vain. She is hoping that, as a result of this tragedy, laws will be passed that will protect others from similarly inhumane and dangerous interventions.

What can you do?

❖ Learn more about Matthew's Law, the law being introduced in New Jersey to make the use of aversive techniques and the inappropriate use of restraint illegal. See the website for Matthew's Law at <http://matthewslaw.bravepages.com>

Matthew Goodman

❖ Share the website with publications, listserves and other information resources.

❖ IN NEW JERSEY: Contact your state assemblypersons and senators, telling them to support A2855, "Matthew's Law limiting the use of restraints." Tell them that the other two restraint bills proposed on the same day as Matthew's Law do not come close to addressing the problem.

ACROSS THE COUNTRY: Contact the bill's sponsor, Assemblyman Eric Munoz, M.D., at the address or e-mail on the web site. Tell him of your support and thank him for caring about this important issue. If you have a story to tell about the damage done by restraint use or about the efficacy of positive approaches, please tell it! It is vital that we counteract misleading information from restraint-dependant programs that are telling the New Jersey legislators that restraint is a necessary part of many people's treatment.

❖ Consider starting a similar effort in your state. Call TASH at 1-800-482-8274 for support.

Faculty Position In Early Intervention

Louis de la Parte Florida Mental Health Institute

DEPARTMENT OF CHILD AND FAMILY STUDIES - Division of Applied Research and Educational Support

Research Assistant Professor/Research Associate Professor

This position is a grant-funded, 12-month faculty position for an early intervention research and demonstration project focused on providing positive behavior support to young children and their families in the Part C service delivery system. This position will coordinate the daily activities of project staff and direct project activities. This position will work in collaboration with a research leadership team (Glen Dunlap, Lise Fox) and project personnel from related research and training projects including the OSEP-funded Center for Evidence-based Practice: Young Children with Challenging Behavior. Additional responsibilities with this position will include conducting research, grant development, writing for publication, workshop and conference presentations, and maintaining familiarity with current research in early intervention for young children with challenging behavior and positive behavior support.

This position is within the Division of Applied Research and Educational Support. The Division of Applied Research and Education Support (DARES) is directed by Dr. Glen Dunlap and houses over 20 externally funded projects in the areas of disabilities, early intervention, autism, family support, and positive behavior support with an annual operating budget of approximately $8 million. The Division employs over 100 faculty and staff who are actively involved in research and program development efforts to improve the lives of children and families who face challenges due to developmental disabilities, challenging behavior, or poverty

Minimum qualifications: Doctorate in special education, early childhood education, child development, psychology, communication disorders or related field. Knowledge of intervention approaches in social-emotional development and experience working with young children with developmental delays.

Preferred qualifications: Experience in program leadership of early intervention research, demonstration, or community programs. Experience in infant mental health or positive behavior support. Experience in staff supervision, providing training and technical assistance to early educators and families, working collaboratively with families and outside agencies, professional workshop and conference presentations, writing grant proposals, writing for publication, and conducting research.

Note: Individuals hired for these positions will be required to undergo a fingerprint and background check.

Application Deadline: December 13, 2002. When applying for the position, please specify Position #11827

Mail, fax, or electronically transmit cover letter, vita, and a list of three references to: Patricia White, FMHI-USF/MHC2113A, 13301 Bruce B. Downs Blvd., Tampa, FL 33612-3899, Fax: (813) 974-6115, E-mail: pwhite@fmhi.usf.edu

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Early Childhood Special Education

The University of Wisconsin Oshkosh College of Education and Human Services has an open position in Early Childhood Special Education (Position 111a.0203, Assistant/Associate Professor, tenure-track, academic year).

Responsibilities include teaching undergraduate and graduate courses in a collaborative program for early childhood special education and early childhood elementary education, supervision of related field experiences, professional development, research, scholarly activities, and service. A doctorate in Special Education or a related area (dissertation written prior to September 2, 2003, with a defense scheduled no later than December, 2003) is required. Prior experience teaching young children with disabilities is essential. Review of applications will begin on January 10, 2003 and continue until position is filled.

Applicants should submit a letter of application specifying position number, resume, statement of teaching philosophy, transcripts, and three current letters of recommendation to: Dr. Michael Ford, Associate Dean, College of Education and Human Services, University of Wisconsin Oshkosh, Oshkosh, WI 54901. *The University of Wisconsin Oshkosh is an Affirmative Action/Equal Opportunity Institution.*

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TASH: Public Policy in Action

UNFINISHED BUSINESS

Lawmakers Negotiate Family Opportunity Act

Negotiations over the Family Opportunity Act (S 321), a bill that would permit middle income families with children who have significant disabilities to buy into the Medicaid program are continuing. Rep. Pete Sessions (R-Texas) has been meeting with House and Senate staff to try to reconcile the current version of the "Family Opportunity Act of 2002" with several measures supported by House Energy and Commerce Chair Billy Tauzin (R-Louisiana).

Under the Senate bill, children with disabilities in families with incomes up to 250% of the federal poverty level, or $45,000 for a family of four, would be eligible to receive Medicaid benefits. Current income eligibility limits are 133% of the poverty level for children younger than age 6 and 100% of the poverty level for children ages 6 to 18. The bill would give states the option of changing those eligibility qualifications for children with disabilities. It is estimated that about 200,000 additional children with disabilities would be eligible for coverage under the expansion. Rep. Tauzin supports a change in the bill that would provide states the option of offering coverage through either their Medicaid or CHIP (Children's Health Insurance Program) programs. It is hoped that Senate and House discussions will result in a compromise that will mean the Family Opportunity Act will be passed in the House when Congress returns after the just-concluded mid-term elections.

Proposals to Amend IDEA are Introduced in Congress

Several bills have been introduced in the House of Representatives. Representative Patrick Kennedy of Rhode Island introduced the "Early Intervention Improvement Act" (H.R. 5076) and the "Reducing Special Education through Prevention Act" (H.R. 5352) in September. The Early Intervention Improvement Act is aimed at ensuring that all children under the age of 3 years who are involved in a "substantiated case of child abuse and neglect" are referred to Child Find for assessment and, if necessary, early intervention services. In addition, the bill targets an additional group of infants and toddlers who may be at risk of developmental delay or disability by virtue of their "family condition" which could include diagnosed serious maternal depression, confirmed parental substance abuse, or documented family violence.

TASH has expressed concerns about the wording of the additional "at risk" category as well as the assumptions about the capacity of both current Child Find and early intervention providers and state mental health systems to diagnose and treat mental illness in infants and toddlers who may be referred to them.

The Reducing Special Education Through Prevention Act proposes to improve school-based interventions for students who may develop emotional or behavioral disorders. Specifically, the proposal amends Part D of the IDEA to allow a state or local education agency to apply for a three-year grant to implement programs, strategies and services designed to reduce the number of youngsters who require the provision of special education and related services for "emotional disturbances."

The IDEA Paperwork Reduction Act of 2002 was introduced by Representative Ric Keller of Florida. This bill has several provisions aimed at "relieving teachers, administrators and related service providers from excessive paperwork burden" and to "reduce time spent by teachers on non-instructional activities." The bill proposes a set of "strategic proposals that are aimed at achieving its purpose:

- Requiring the Secretary of Education to develop and disseminate "streamlined" models of documents for Individual Education Program (IEP) development, procedural safeguard notices, and prior written notice provisions to parents and guardians

- Permitting states to let their local school divisions, with the informed and written consent of parents, to develop a 3-year IEP which will contain three year goals, some coinciding with what is called "natural transition points" for the student, as well as annual goals for measuring progress in the general curriculum. Further, a "comprehensive review and revision" of the IEP would only occur at those "natural transition points" rather than annually.

- Increasing emphasis on whether or not a student receiving special education services and supports is making satisfactory progress towards achieving the three-year goals (as measured by the annual goals, possibly).

- Grant waivers of unspecified "paperwork requirements" for 4 years to no more than ten states for the purpose of demonstrating "effectiveness" of various proposals in reducing "paperwork" and non-instructional time spent by teachers in compliance with IDEA.

In addition, the bill gives local school officials "discretion" about whether any member of the IEP team can be "excused" from meetings unless the parents or guardians object. The bill continues in this manner, leading TASH to wonder how much "burden" is

Continued on page 7

UNFINISHED BUSINESS

Continued from page 6

going to be relieved by the micro-managing of every interaction between families and school personnel in planning educational supports and services and in protecting the civil rights of students with disabilities. And, of course, TASH strenuously opposes any proposal that would "strip down" those rights and fail to fully inform parents and students of their procedural safeguards.

This bill is significant because the co-sponsors are Representative John A. Bochner (Ohio), who is Chairman of the House Committee on Education and the Workforce, and Representative Mike Castle, who chairs the Subcommittee on Education Reform, which has jurisdiction over special education programs. TASH members are urged to make note of the House Education and Workforce Committee web site: www.edworkforce.house.gov. Comments about changes to IDEA are still being solicited and taken. In addition, the web site is an accurate and timely source of information about education issues moving through the Congress.

TASH Continues to Oppose use of Restraints, Seclusion and Abuse

TASH Executive Director, Nancy Weiss along with Pat Amos of the Family Alliance to Stop Abuse and Neglect, New Jersey TASH members and 200 advocates rallied at the New Jersey State House on Monday, October 7. Speakers included Janice Roach, mother of Matthew Goodman, who died on February 6 of this year. Matthew was being "treated" at the Bancroft School. Prior to his death, Matthew spent literally months in physical arm restraints and a helmet with a darkened visor

restricting his vision (see Nancy Weiss's article beginning on page 3).

New Jersey Assemblyman Dr. Eric Munoz has introduced legislation that would severely restrict the us of restraints in facilities for children and adults with developmental disabilities and traumatic brain injury to a narrowly defined set of emergency only circumstances. Under this law, restraints and seclusion could not longer be written into IEPs and Individual Habilitation Plans as "treatment."

For further information and updates about Matthew's Law visit http://matthewslaw.bravepages.com.
To help TASH in our fight against abuse and restraint of children and adults with disabilities, contact Nancy Weiss (nweiss@tash.org)or Jamie Ruppmann (jruppmann@tash.org).

TASH in Action! Is your vote important? Are you registered? How does TASH decide what issues to support and what issues to oppose? What's happening with MiCASSA, and when is the Congress going to do something about housing and people with disabilities?

These questions and more will be answered if you drop by the TASH in Action! exhibit at next month's annual conference in Boston. Talk with Governmental Relations staff and members who are interested and knowledgeable about policy issues that effect the live of people with disabilities. For conference information, including a registration form, visit <www.tash.org>

Thank You!

TASH's work is dependent on the financial assistance of our donors and members. We wish to acknowledge the generous donations of the following individuals:

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Debra Shelden
Martha E. Snell
Cynthia F. Sutton
Charles Zeph

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JUST ADDED!

Research to Educational Practice: A Conference within the Conference for Present and Future Teachers and Practitioners

Sheraton Boston and Hynes Convention Center
Saturday, December 14th
9:00 am - 3:30 pm

Special Saturday Only registration fee:

$59.00 for TASH members
$89.00 for non-members
This special Conference within the Conference is open to all full conference registrants at no additional charge. To register for the Conference within the Conference, use the registration form located on the TASH web site at <www.tash.org/2002conference/regonline.htm>, and select the "Saturday Only" category.

At the 2002 TASH Annual Conference, the Saturday Conference within the Conference features a series of dynamic sessions focused on practical, day-to-day strategies for translating current research knowledge into educational practices that enrich the lives of students with significant disabilities and their families.

Sessions will afford participants the opportunity to hear about the most progressive practices directly from nationally known authors in the field. Featured presenters:

Rick Albin - Positive Behavioral Support
Glen Dunlap - Positive Behavioral Supports
Mary Falvey - Curriculum and Instruction
Chris Kliewer - Literacy and Communication
Diane Ryndak - Curriculum and Instruction
Marti Snell - Curriculum and Instruction
and more!

Participants will have the opportunity to select sessions from one of three strands: Communication and Literacy, Curriculum and Instruction, and Positive Behavioral Supports. Lunchtime will include a poster session in which graduate students will display the results of their research and other innovative projects focusing on students labeled with severe disabilities.

For an updated listing of conference sessions, accommodation, travel, child care, and other iinformation, as well as the conference registration form, please visit www.tash.org/2002conference

Employment Strand and Sessions

The following represents a partial listing of the employment related sessions scheduled throughout the upcoming TASH Annual Conference.

This year's conference, "Our Quest: Opportunity, Equality, Justice" is scheduled December 11-14 2002 (preconference workshops on December 10, 2002) in Boston, Massachusetts at the Sheraton Boston and the Hynes Convention Center.

For a listing of sessions in other topic areas, including strands, exhibits, and special events, please visit www.tash.org/2002conference. Please note that this is a preliminary schedule that is subject to change.

Employment Strand

Thursday and Friday
Convention Center Rooms 201 and 202
Strand Coordinator: John Butterworth
This strand features sessions that cover all the important issues related to the employment of people with disabilities. Sessions covering policy, systems, and personal perspectives will be held on both days in Room 201. Those sessions focusing on practice will be held in Room 202.

❖ ❖ ❖ ❖ ❖

Wednesday, December 11, 2002
10:00 am-4:00 pm Pre-Conference Session
The Ticket To Work: What Are The Opportunities?
Speakers: David Hoff, Elena Varney

The Ticket to Work, which is currently being introduced by the Social Security Administration, provides a potential opportunity for people with disabilities to have increased choice regarding services that will help them find and keep a job. Attendees at this workshop will learn about the Ticket program, the opportunities and challenges it presents, and ideas for utilizing it to enhance individual opportunities and empowerment.

Thursday 10:15am-1:15pm
Pushing the Employment Agenda: State Perspectives
Speakers: John Butterworth, Allison Cohen, Dana Scott Gilmore, Deborah Merzel

This session will focus on the factors that contribute to high performance in integrated employment among states. Research findings will be presented, followed by a panel of stakeholders from several states who have been directly involved in facilitating systems-level change.

Status Quo, Stigma in Employment
Speaker: Sarah Berger

What are your stigmas in hiring persons with mental illness? This interactive workshop will test your marketing, personal perceptions, and accommodations skills.

Thursday,December 12, 2002
11:30 am — 12:30 pm
Opportunity, Equality and Justice: Maine's Systems Change Efforts in Employment Supports
Speakers: Deborah A. Gilmer, Alan Kurtz, Kathy Son, Lenny Berry, James Meehan, Brenda Harvey, Mel Gleason

This panel presentation will share information on a number of systems change initiatives undertaken in Maine to build the capacity of community rehabilitation agencies to implement a new vision of employment supports, including curriculum development, a number of statewide staff development activities and policy change.

The Right Person for the Job: Developing Business Capacity to Include Employees with Autism
Speakers: Bud Cooney, David Hagner

This session will present findings from a one-year project developed to improve the capacity of employers successfully include employees with autism. The essential components for success reported by 14 employers along with a training module developed for potential and current employers of persons with autism will be presented.

Thursday,December 12, 2002
2:15 pm — 3:15 pm
Integration of People with Disabilities into One-Stop Systems: A National Progress Report
Speakers: David Hoff, Sheila Fesko, Lora Brugnaro, Allison Cohen

One of the newer strategies for meeting employment needs of people with disabilities is use of One-Stop Centers. Is the generic workforce development system really working for people with disabilities? This session will look at current progress and future trends.

Social Security Benefits: Making Sense of the Maze
Speaker: Elena Varney

As people with disabilities seek employment, the impact of income on Social Security Benefits is often a major concern. This session will cover: the differences between SSI and SSDI; how employment impacts benefits; work incentives available; and tips for dealing with SSA.

Thursday,December 12, 2002
3:30 pm-4:30 pm
Incorporating Social Security Work Incentives in Transition Planning
Speaker: Ellen Condon

Social Security Work Incentives are an effective resource in Transition Planning. Student case studies which illustrate the utilization of work incentives to promote choice and consumer controlled supports will be shared along with strategies developed by schools and communities to access these resources.

Thursday,December 12, 2002
4:45 pm-5:45 pm
Closing Up Shop: It's the Process, Not the Product, That Counts
Speakers: Paul Dickin, Phil Smith, Bryan Dague, Mike Moody, Alan Bushey, Paul Bakeman

Come learn about what it was like to close down the last sheltered workshop in Vermont! Self-advocates, family members, staff, and other stakeholders will describe an ongoing process of conversion of a small, family-centered agency.

You Can Get There From Here: Finding Your Way After High School
Speakers: Beth- Anne Dabek, Erica Sandelin

The journey from high school to adult life can be both challenging and exciting. Come learn what students from five urban high schools in Massachusetts are doing to pursue their dreams of working and recreating in their communities.

Friday, December 13, 2002
8:00 am-10:15 am
Promoting Meaningful Daytimes: Strategies and Issues
Speakers: Pam Walker, Patricia Rogan, Elizabeth Obermayer, Jeffrey L. Strully, Jennie Todd

Despite great strides toward integrated employment, many adults remain in segregated settings or bored and isolated at home. This presentation discusses support for a wide variety of daytime pursuits, including: paid and volunteer work, postsecondary education, and community connections.

Friday, December 13, 2002
10:30 am-11:30 am
Do What You Love....Love What You Do
Speakers: Ken Renaud, Joshua Joyal, Delia Boro, Paula Ortega, Charlotte Testa

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Employment Strand and Sessions

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This session looks at the PAL Employment Information Network, an initiative that is comprised of individuals with disabilities who are successfully employed. We will demonstrate how these individuals play an important role in the transition process by sharing their personal success stories with high school students with disabilities and by serving as mentors. They encourage the students to choose jobs that utilize their talents and skills.

When Existing Jobs Don't Fit: Job Creation for People with Significant Barriers to Employment

Speakers: Melanie Jordan, Kimberly O'Neil

"Pre-existing" job openings often do not meet the needs of individuals with significant disabilities. This interactive session will offer practical information, strategies, and many examples and success stories related to creating and restructuring jobs to meet distinct interests and needs.

Friday, December 13, 2002
11:45 am-1:30 pm
TASH Town Meeting
Speakers: Martin Gerry, Social Security Administration, Stephanie Lee, OSEP, Judith Heumann, The World Bank, Anne C. Smith, Zuhy Sayeed and other leaders will join Jamie Ruppmann, TASH Director of Governmental Relations, to discuss the current state of the states in disability policy.

Friday, December 13, 2002
1:30 pm-2:30 pm
Building Community Connections: A Networking Approach for Transition Age Students
Speaker: Colleen O'Mara Condon

This session offers an overview of a workshop on how students can use networking, the most effective job or career search strategy. It will include sample exercises as well as discuss the facilitator's role in empowering students to use their networks.

Optimal Roles of Job Developers and Job Coaches to Promote Natural Supports in the Workplace
Speakers: Carl Cignoni, Brian Patingre, Madonna Trotter

Natural supports are a determinant of success for people with disabilities at work. Many roles job developers and coaches assume either promote or discourage natural supports, often unawares. Participants will examine the optimal roles to promote natural supports.

What is Our Obligation to People Who Do Not Seem to Want to Work
Speakers: Jeannine Burns, Aimee Pavlak, Matt Slosek, Melissa Stefano

People with disabilities may not want to work due to fear of failure, undesirable employment options, no positive work experience, and low expectations. This session will explore these and present strategies to create positive experiences for people to work successfully.

Friday, December 13, 2002
2:45 pm-3:45 pm
Accessing Community Transportation, Inc.-A peer travel training Self Directed Support Corporation
Speakers: John Susa, Terri Trautman, Connie Susa, Mark Susa

Despite multiple disabilities, Mark Susa is president of a business that teaches others with disabilities how to use public transportation. Learn how his school to career transition and state-funded supports were used to create this self directed support corporation.

One Stop Career Centers: A Resource for All Job Seekers
Speakers: Cynthia Thomas, Pauline Donnelly, Lara Enein Donovan

This session will provide an overview of the One Stop Career Centers and how they can be used by individuals with disabilities seeking employment. Promising practices will be described to provide attendees with a better understanding of the system and what they can do to make it work for them or individuals they support.

Friday, December 13, 2002
4:00 pm-5:00 pm
It's a Job You Really Wanted, But Now Are You Happy?
Speakers: Bruce M. Menchetti, Elizabeth Haines, Lori Garcia, Renee Llewellyn

In this session you will learn how people with disabilities helped develop a job satisfaction survey to guide employment services. Most importantly, however, you will hear from a self-advocate, as she discusses what is important to her personal job satisfaction.

Sometimes I Get Fired: Co-memoir Eugene Marcus' Supported Work Experiences
Speakers: David Marcus, Eugene Marcus

Join this session as father and son discuss Gene's life experiences in regards to supported work. Using facilitated communication, the presenter will discuss his successes and failures in the work place. Come to this interactive session prepared to ask questions.

Saturday, December 14, 2002
10:00 am-11:00 am
How To File A Winning ADA Employment Discrimination Complaint
Speakers: Kathryn Moss, Tia Nelis, Joy Weeber

Under Title I of the ADA, individuals who have experienced employment discrimination based on a disability may file a complaint. This workshop will teach participants about how to file a winning complaint.

The following Poster Sessions related to employment are scheduled from 8:00-10:00 am on Saturday, December 14, 2002.

Creating Vocational Opportunities for Students with Disabilities
Speakers: Chris Peltier, Laurel Peltier

This multimedia workshop will present various approaches to creating community-based vocational opportunities through collaborations with schools and businesses. This presentation will utilize group exercises to inspire creative thinking about students' careers and will engage the participant for positive action.

It's Not About Jobs, It's About Income
Speakers: Darcy Smith, Doreen Rosimos

This presentation will focus on how Doreen Rosimos and Darcy Smith have made the production of INCOME happen across the country. They will discuss case studies, and the importance of engaging the community in your life and enterprise. Combining Joy, Permission and Investment has lead to life altering experiences for many individuals. We will engage you with lively conversation and a different view to bring income into people's lives, no matter the challenges.

Let's Get Working! How to Transform your Vocational Department into Cutting Edge Program Emphasizing Person-Centered Planning
Speakers: Kate Clark, Stan LeRoy, Jo-Ann Bernard

This presentation will highlight the areas that we have developed in our program including assessment and evaluation, job preference inventory, employability skills curriculum, career development, and supported employment. The presentation will include strategies to involve family and friends and the job seeker for future planning within the IEP Vision Statement. It is our hope that individuals who attend our conference will take away multiple resources that they will be able to utilize easily upon conclusion of our presentation.

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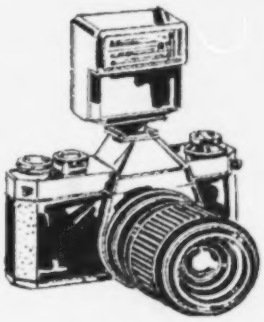

Through Our Lenses

BY ABBY L.W. CROWLEY

A unique program at the Lt. Joseph P. Kennedy Institute in Washington, D.C. is expanding career options for people with developmental disabilities. The U.S Department of Labor, in its Occupational Outlook Handbook, paints a promising picture of growth in need for people who can operate cameras and process photographs using traditional and digital technologies.

Careers in portrait, commercial, industrial and news photography offer about 161,000 jobs nationwide. The entertainment market, particularly the cable industry and the Internet, has increased the demand for camera operators. The increase in availability of one-hour processing facilities in malls, supermarkets and retail outlets provides an additional 42,000 jobs nationwide.

In most cases, employers prefer applicants for these jobs who have had some experience in the field. Albert "Al" Price, an experienced photographer and a person with many years of experience working with people with developmental disabilities, thought that he could combine his two areas of expertise to develop a new kind of training program within Kennedy Institute's employment services division.

Starting with a $3,000 investment, he purchased ten cameras and 500 rolls of film and started working with a group of eight adults in the basics of 35mm black and white photography in a 16-week, 250-hour program called Through Our Lenses. In the beginning, he had the students' film developed and printed commercially. Their first exhibit, My First Exposure, garnered acclaim and media exposure for the program. This led to donations and grant opportunities to purchase darkroom equipment and supplies. Grants and donations also allowed Mr. Price to take his group to New York City to take pictures and to see the Andy Warhol Perfecting Mankind exhibit at the International Center of Photography.

When you meet Mr. Price, you are immediately struck by his passion and enthusiasm for his program and the participants. His excitement and willingness to "just pick up the phone" and ask for what he needs have been key to the program's success. The Washington Post was a major benefactor, providing photographic equipment. Mr. Price was able to recruit members of The Exposure Group, a Washington-based African-American photography association, to mentor his students. Photographic printing and framing for the exhibit were all donated. For the trip to New York, Amtrak donated train tickets and a company donated a limousine for the day. The program received grants from Kodak and the District of Columbia Arts and Humanities Council. Most recently, the program received a substantial grant from the District of Columbia Youth Investment Trust Corporation. This grant will provide a 2 1/2-month training program for three cohorts of ten individuals from 14-21 years old. Mr. Price's current ambition is to acquire a photographic print machine so that his students can have hands-on experience that can turn into marketable skills in the one-hour photo processing market.

Mr. Price has taken his training one step further. He has developed a partnership with CVS Pharmacy and has begun to place people in competitive employment in their photo labs. He has plans to develop relationships with other photo labs as well.

Mr. Price is quick to point out that the benefits of building skills in photography are not only in the area of employment. People also have become photography hobbyists and find photography to be an excellent vehicle for making connections with people and for personal expression. He has seen self-esteem and social skills enhanced by involvement with photography. Program participants have also developed an appreciation for photography and art as a result of their involvement.

These new photographers can best describe the value of having access to training in the field of photography. Kelly, age 18 says, "I like using the camera to take photographs of outdoor scenes and people having fun. I like to show off my photographs." Stormy, age 21, who is now competitively employed at a one-hour photo lab, says, "I think I found my talent. I surprised myself because I didn't think I had a talent." And finally, Lisa, age 23, expresses her hopes: "I would like to be a photographer one day for the Washington Post or for the President of the United States." Through Our Lenses has the power to make dreams like these come true.

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Making Dreams a Reality: Using Personal Networks to Achieve Goals as You Prepare to Leave High School

BY JAIMIE CIULLA TIMMONS, MAIREAD MOLONEY, DANIELLE DREILINGER, AND JENNIFER SCHUSTER

Introduction

Getting ready to leave high school can be both exciting and stressful. Young adults with disabilities need to figure out what their interests are and develop goals for the future. Decisions need to be made about where the young adult might live, what kind of job he/she might have, or where he/she may continue his/her education. New life options create opportunities for more decision-making.

Although young adults with disabilities may become more independent during this time, the support and encouragement of others remains crucial for success. The Institute for Community Inclusion (ICI) interviewed high school students with disabilities and their parents and/or guardians. ICI asked these families about their plans for the future and how others may have influenced their decisions. In addition, both students and their parents were asked to tell ICI about important decisions they have made as a family, and who they depend on when there is a problem and support may be needed.

Three stories

Many of the students and parents who participated in ICI's study described how they used and depended upon their personal networks — both formal and informal — to figure out what they need and want, and help them discover, reach for, and achieve their personal goals. In addition, these personal networks helped to develop self-determination in the young adult. The three stories that follow illustrate ways that students used personal networks to help them achieve their goals, and sometimes, how they could be better used to make their goals a reality. These examples also illustrate how personal network members can help a young person achieve self-determination.

What is self-determination?

People who have self-determination know what they want and how to get it. They know a lot about themselves and have a clear vision for the future. Self-determined people can make decisions for themselves, and know what they have to do to achieve their goals. They feel independent and in control of their life plans. A self-determined person does not need to know all the answers, but he/she knows that there are a variety of options in life that are available. They understand their own strengths and weaknesses, try to solve problems, and make their own choices. Self-determination is related to self-esteem and confidence because in order to pursue your goals, you need to feel that you can be successful in your endeavors. In addition, self-determined people know how to find help when they need it. This help usually comes from their personal network.

What is a personal network?

A personal network is basically everyone that a person knows. This includes both formal and informal network members. Formal network members are professionals such as school counselors or teachers. Informal network members are people close to you, like your friends, family members, and others you may have met in social organizations, sports teams, religious organizations, or even in your neighborhood.

How can a personal network help to develop self-determination?

Personal networks can guide self-determined people as they solve problems and support them when important decisions are made. People from the personal network help teach new skills as goals are achieved. Self-determined people learn to plan and coordinate their lives with help from these important people. Members from the personal network provide more and more opportunities for the self-determined individual to make decisions and learn new skills on his/her own.

(The stories that follow are based on conversations with high school students and their parents and/or guardians. Each student and his/her parent/guardian were interviewed for approximately 45 minutes. A total of nine students and eight parent/guardians (6 mothers, 1 father, and 1 foster mother) were interviewed. Please note that names have been changed to protect their privacy.)

Story 1: "I found what I needed to move forward."

Heather, a recent high school graduate with physical and special health care needs, expected to have a full-time job, live with her boyfriend, and someday have kids. She felt very strongly about the value of work. As she said, "I want to work 100%. I want to work for my money." Heather's mother, however, was concerned that a full-time job would have a negative effect on Heather's Social Security benefits.

Self-determined people may not necessarily know exactly what they want at all times, and their visions may change from one day to the next, but they know how to get what they need.

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Despite her mother's concerns, Heather was determined to pursue a full-time job. Throughout high school, Heather's personal network exposed her to a variety of employment opportunities. When she was looking for a summer job, a family friend who worked in landscaping helped her find a job in the business. Her brother introduced her to the auto body field by letting her work on his car. This led Heather to take classes in auto body repair at school to gain more experience.

These experiences gave Heather the knowledge to develop work and career goals. Heather gathered the support she needed from her boyfriend and brother who went with her as she collected job applications, helped her fill them out, and provided encouragement. Heather's brother advocated on her behalf to their mother. "He's the one that's fighting with my mother telling her that I should work." Heather also applied for jobs independently and used school personnel to help her uncover the Department of Vocational Rehabilitation (VR) as an additional resource. She set up an appointment with a VR counselor on her own. All these activities led her to find a job in a field that matched her interests.

Important points:

- Heather's network gives her opportunities to discover her preferences by exposing her to a variety of work experiences.
- Heather chooses to work. Her self-determination is evident in her strong desire to work despite her mother's concern.
- Heather demonstrates self-determination not only by independently finding Vocational Rehabilitation as a resource, but by gathering support from her boyfriend and brother.
- Heather makes substitutions for gaps in her personal network. Because she feels her mother was not supportive, she finds other people (her brother, boyfriend, and school personnel) to help. Positive network members balance out other members who have reservations.
- Heather uses a combination of informal network members (brother and boyfriend) as well as formal network members (school personnel, counselor from VR) to reach her employment goals.
- Heather's informal network provided both encouragement and specific help (like filling out applications).

Story 2: Shared goals and a champion's support bring success

Shantelle, a recent high school graduate with a psychiatric disability, worked part-time while living at home. A large, dependable network of both formal and informal members helped support her as she developed her goals. This included a close friend, teachers, a therapist, and a neighbor who employed her as a babysitter. Shantelle talked to a close friend and teachers about her decisions for a career, and a therapist about more personal problems.

Most importantly, Shantelle has had great support from her mother. They agreed in their hopes and goals for her future. Shantelle said her mother supported her to reach greater independence: "She doesn't suggest anything. She thinks it should be my concern and my issues what I should do. She thinks I am responsible for myself. She lets me make my own decisions...[but] if I don't know if it's a good or bad idea I ask for her opinion." Shantelle's mother confirmed this by saying "if she says she wants to try something I don't stop her.... We let her make her own decisions. The only way you are going to learn is to make the mistake on your own."

The only challenge Shantelle's mother saw that could stand in Shantelle's way was her tendency towards low self-esteem. This motivated her to surround Shantelle with support. Shantelle's mother gained insight through talking to teachers, the family doctor, church members, and even neighbors. "That's what it takes, you know. Keeping that self-esteem up and saying, 'We know you can do it.'" Shantelle's family and friends were quite proud of her. Shantelle's mother best summed up her philosophy and optimistic outlook for her daughter when she said, "We're all looking for a bright future for her."

Important points:

- Shantelle's mother supports Shantelle's self-determination by listening and making suggestions, and not making decisions for her. Shantelle's family and friends focus on building her self-esteem and confidence so she can move forward and be more self-determined.
- Shantelle has a large personal network that includes both informal network members (close friend, neighbor, and especially a strong relationship with her mother) and formal network members (teacher and therapist).
- Shantelle uses members from her personal network differently; some she talks to specifically about work (friends and teachers), while others support her more personal concerns (therapist).
- Shantelle's mother uses her own network to learn how to support Shantelle and encourage self-determination.
- Shantelle's mother makes sure not only that she is surrounded by support, but uses her own network as an expansion of support for her daughter.
- Shantelle and her mother are in alignment. This means that they agree, and share high expectations for the future. This alignment and shared goals are crucial in maximizing Shantelle's self-determination.

Story 3: On the road to self-determination.

Carlos, a recent high school graduate with a cognitive disability, had a variety of interests including art and electronics and was very serious about working. However, while he had ideas about careers that would fulfill his interests, he did not know how to achieve his goals. He had high expectations for his future and didn't want to settle for any old job. High school frustrated him because he felt that the work experiences and skills he learned there would not prepare him for the working world: "I am not going to get anywhere with those jobs." Although he advocated to change his situation at IEP meetings, school personnel did not change his program.

Carlos' mother was also disappointed by his school, and supported his advocacy efforts. However, she was concerned that Carlos's

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standards might be too high. "He doesn't want to take any suggestions.... I don't think he understands [that] he doesn't get to pick and choose." She also doubted whether he would be able to pursue the jobs he liked. "It's kind of, like, out of his grasp, but I don't say that."

Carlos and his mother used two formal network members to help him succeed. This included a professional from a private organization and a counselor from the Department of Mental Retardation (DMR). Carlos's mother coordinated these services. Carlos's mother also used his monthly SSI check as a "bank account" to give him experience in using money. However, Carlos's mother reported that they didn't use their own personal network as a resource: "We're it, my husband and I." One result is that, according to Carlos's mother, Carlos relied on her too much.

While Carlos's mother wanted Carlos to be independent, she feared that he would make bad choices if left to his own resources. "I don't think he is mature enough to understand what the big decisions are and how he can handle them." She didn't know how to support him to make good decisions on his own without her making them for him. "I kind of guide him.... I kind of sway him, kind of try to con him into it."

Carlos felt the lack of support. Despite a college course in computers, he didn't feel confident that he could find a job he liked. Carlos felt stuck. "I don't want to be alone... for the rest of my life. And I don't have a good job that I am good at."

Important points:

- Carlos demonstrates self-determination through his strong desire to work, not settling for the limited options offered him by his school program, and self-advocating at school IEP meetings.
- Carlos shows self-awareness in that he had clear interests. Having self-awareness is a crucial first step to being self-determined.
- Carlos's family helps to develop self-determination by allowing him access to his SSI checks. Carlos's mother uses SSI as a tool to increase independence, learn the value of money, and teach financial planning. However, Carlos's mother is responsible for coordinating the support from his formal network rather than Carlos doing it himself.
- Carlos and his family use formal network members to help him reach his goals. However, Carlos and his mother may not know how useful informal network members such as friends and family could be. A broader range of informal contacts could give Carlos a fuller array of assistance and help him get a clearer focus on his goals, skills, and opportunities.
- There is a lack of alignment between Carlos and his mother. This means they did not agree or share the same expectations for Carlos's future. Although they shared the vision that he would work and live independently in the future, they disagreed about what jobs he is capable of pursuing at that stage. Carlos's mother thought that Carlos was too picky. Carlos, on the other hand, didn't want to waste his time on jobs that didn't match his interests.
- Carlos feels powerless, like he was not "in the driver's seat." This is the opposite of self-determination. Carlos does not see himself as being on a positive path to a fulfilling future.

What can Carlos & his family do?

Carlos's mother can begin to give Carlos more responsibility in coordinating the support he receives from formal network members. In addition, while continuing to rely on their formal network members, Carlos and his family could develop their informal network. In this way, Carlos could gain a fuller array of assistance, particularly in areas in which he is is interested, with the addition of the personal knowledge and insight that family, friends, and neighbors can give. Their support could help Carlos get a clearer focus on his goals, skills, and opportunities. How can a family develop their personal network? It may not be as hard as you think!

The families who participated in this study were probably much like your own. They had varying racial/ethnic backgrounds, and the students ranged from freshmen to seniors in high school. The young adults had a wide range of disabilities including physical, cognitive, learning, emotional/psychiatric, behavioral, and sensory impairments. Some families lived in suburban locations while others lived in cities.

Here is what you and your family can do.

You and your family can identify and expand your personal networks and think about ways to reach out to them and practice self-determination.

Map out your current personal network.

Make a list of everyone you know. This should include all people that you know well enough to have a conversation with. Include family members, friends, community members such as neighbors, and professionals such as teachers, counselors, employers, and co-workers.

Build your personal network.

- Go on a few informational interviews. The goal of this type of interview is to learn about a type of job or a certain company, not to get a job. Informational interviews are an excellent way to explore different interests and jobs while making new contacts. People in your network can help you set up interviews where they work.
- Join different community groups such as local neighborhood organizations, clubs, religious organizations, or recreational facilities.
- Volunteer for a cause you believe in, or an activity that interests you.
- Participate in community events, such as those sponsored by local groups, schools, and libraries.
- Focus on developing relationships. Establish trust. Spend time doing this before you make specific requests of people.
- Think about ways that you can help your network members. Offer your help. Remember, you can be helpful to your network members just as they are helpful to you.

Reach out to your network.

- Ask for help when you are facing big decisions in your life.
- Take the time to tell people what you are thinking about, share your goals, and the challenges you may be encountering.
- Be specific about the ways that you would like people to help you.
- Ask people in your current network about

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career ideas, and explain your interests. Network members may know about employment opportunities or be helpful in exploring job ideas with you.

- Ask people in your network to introduce you, or refer you, to people they know who may be helpful to you. This can lead to new opportunities.
- Don't be afraid to ask more than once.
- Realize that members in your network will play different roles and you will not get the same thing from each member.
- Realize that network members aren't always able to help. There may be times when you ask for help and they are not able to give it to you. This is okay!
- Keep your network updated on your progress. People like to help and it will make them feel good to know that you are working toward your goals.

You are already exercising self-determination just by reaching out to those you know. Remember, a self-determined person knows what he/she wants and can find the support to achieve his/her goals! It's up to you to find this support.

A good network member:

- Thinks of him/herself as a resource.
- Is willing to listen. He/she may offer suggestions or different ways to think about your decision or issue.
- Will make time in their schedule for you.
- Offers encouragement, guidance, and advice when you need it.
- Is a positive role model.
- Should never be someone you feel uncomfortable with or someone who puts you down.
- Is someone you can trust.
- Is someone who is happy to share his/her experience with you.

A good network member supports self-determination by:

- Asking questions but not directing or making decisions.
- Allowing you to experiment with more responsibility, encouraging you to be more responsible for yourself.
- Allowing you to make mistakes in order to learn from them.
- Offering fewer suggestions to encourage independent decision-making.
- Letting you know that he/she thinks you are capable and support the decisions you make independently.
- Building your ability to gradually handle your own affairs.
- Boosting your self-confidence.

Ideas for building independence and self-determination

- Schedule an informational interview in an area of interest. Plan and rehearse phone calls and interviews with someone in your network.
- Take responsibility for setting up job interviews and doing job searches. Participate actively in all aspects of your job search.
- Get involved in school meetings. Bring a list of questions and concerns to your IEP meeting. Consider conducting your own IEP meeting with guidance and support from your school personnel. Remember, they are there to help!
- Learn responsibility through household chores, cooking meals, or having a pet. Hard work often produces rewards!
- Experiment with public transportation when you don't have to be anywhere important. This is a good way to be able to eventually get to a job or friend's house without having to rely on others.
- Practice opening and managing a checking or savings account. Having a savings account is a good way to begin saving money for college, a first car, or moving out on your own.
- Share in family bill-paying. This helps to understand the value of groceries, clothing, personal items, or rent.

Figuring out what you want: The first step to self-determination

Start by figuring out what you want for yourself. These should be your dreams, not someone else's dreams for you. Explore different career options. Think about what you are good at and what makes you happy. Think about who you are and create a personal vision statement. Write this statement down on paper. Remember, a self-determined person understands his/her own strengths and weaknesses, and knows a lot about him/herself. Self-determined people may not necessarily know exactly what they want at all times, and their visions may change from one day to the next, but they know how to get what they need.

Going out and getting it: The second step to self-determination

Once you have figured out what you want, it is time to develop clear goals and come up with an action plan. Think about where you would like to see yourself down the road. Again, write down your plan step by step. Take out your list of network members and think about how each member might be able to help. Put a star next to the names of those that you feel especially close to, and whom you would be comfortable asking for help. Different people in your network can probably help you in different ways. Be willing to ask for help and be specific. Remember, you don't need to have all the answers. Self-determined people know how to get what they want and know how to find help when they need it. They can define their goals and take initiative in achieving them.

Starting early

Although the students in these stories are recent high school graduates, you and your family should not wait until then to start building these skills. In fact, it is important to build these skills early in high school. The point is... it is never too early to start practicing self-determination and expanding your network! So get started!

Conclusion

Being self-determined is exciting, although making your own choices can be difficult sometimes. Don't be afraid to find and ask for help. Reach out to your personal network and ask them to help you reach your goals. Don't get discouraged if you feel like you don't know what you want, you change your mind, or you've made bad choices in the past. It's okay to make mistakes. Remember you are capable and you can do it!

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Employment: From Competitive to Customized

BY MICHAEL CALLAHAN

The Americans with Disabilities Act of 1990 (ADA) provides a strong mandate that describes the rights and responsibilities for employers and prospective applicants with disabilities regarding the hiring process and the employment relationship. However, after more than a decade of implementation, there continue to be unmet expectations — outright frustration, some would say — on both sides of this sensitive issue. Employers continue to be cautious about the narrow consideration the ADA requires concerning employee performance, essential job responsibilities and reasonable accommodation. They are not able to ask about issues relating to disability, other than the accommodations necessary to perform essential job responsibilities, during the interview and prior to extending a job offer. On the other hand, many applicants with disabilities are frustrated by their difficulty in meeting arbitrary job descriptions designed for employees without disabilities.

To further confuse the situation, the current thinking within the disability community does not seem to encourage applicants to negotiate tailored job descriptions by presenting an employment proposal that identifies the specific skills that could match specific needs for the employer. Rather, applicants are encouraged to focus almost solely on obtaining employment from the perspective of legal entitlement. The bitter data from the decade of the post-ADA 1990's, a period of our country's strongest economic growth in history, indicates that the number of Americans with disabilities who were employed at the end of this robust decade was fewer than when the Act was signed in 1990 (Houtenville, 2000).

This confused situation seems to leave the people who are supported by an organization such as TASH out of the employment picture altogether. If people with disabilities who are fully able to compete are finding it difficult to become employed, how can we expect employment to become an expected outcome for people who experience significant disabilities?

The answer can be found by examining the nature of the employment relationship between employers and applicants. When framing the ADA, Congress used the concept of "competitive employment." Within the ADA, applicants with disabilities must compete against two apparent issues:

a) the essential responsibilities of the job, as described by the employer, and
b) other applicants, those with and without disabilities, who might also apply for the same job.

Not only must an applicant be able to effectively perform the essential responsibilities of a job for which he/she is applying, he/she must also compete successfully against other qualified applicants.

Many applicants with disabilities indicate they are also competing against a potential employer's fear of the unknown concerning issues relating to disability. While both sides — employers and applicants — have voiced their concerns, the structure of the ADA in its current form represents a compromise with a slant towards civil rights instead of the nature of the employment relationship.

This critical legislation walks a fine line providing "the art of the possible," the promise and usefulness of which will continue to unfold in the years to come. We are likely to find that the ADA is a better piece of civil rights legislation than it is an effective tool to directly advance employment. It is time now to go beyond waiting on case law to decide specific issues. There are other ways for employers and applicants with disabilities to forge relationships, in addition to that of rights and responsibilities. The employment relationship can be voluntarily negotiated.

Within the disability field during the 1990's, practitioners revisited the challenge of the 1980's to work with applicants with significant barriers to employment, targeting those not likely to compete effectively even with reasonable accommodation provided by willing employers. It was discovered that if applicants with significant disabilities were represented by job developers who offered a specific employment proposal and, if employers were approached in an open manner using negotiation as opposed to legal entitlement, successful employment relationships could result (Examples: Callahan, 1990, Mast & West, 1995).

We found that people with significant disabilities could become employed using tailored or personalized job descriptions and that employers, by and large, were willing to embrace this concept. However, many in the generic employment and traditional rehabilitation fields felt that this approach did not represent "true" employment. Critics seemed to feel that these individual strategies were a sort of aberration, only useful for persons with the most significant barriers to employment to function in a quasi-employment relationship in a grey area between "real" employment and charity-based volunteer work.

Indeed, the history of TASH has been marked by contentious debates regarding the nature of employment and the strategies necessary to assist people to work, for example, the "Brown & Bellamy" debates of the mid-'80's. Some felt that it was necessary to fundamentally alter the employment relationship, including payment for work performed, in order to assure full access for all persons who might want to work. Others felt that it was important to stay within the traditional boundaries set by employer expectations, typical wages and competition. It is probably fair to say that these critically important

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debates fizzled as the tidal wave of supported employment shifted our focus from policy and theory to the tough reality of keeping persons in jobs defined by the Rehabilitation Act of 1986 -- mostly comprised of 20 hours of work per week at or around minimum wage.

However, even as the debate waned, the issue of employment for persons with the most significant impact of disability did not go away. From the beginning of supported employment, observers and researchers scolded practitioners for overlooking those applicants with the highest support needs and those with the most difficulty with competition.

Can the employment relationship be individualized?

The concern that individualized, negotiated employment does not reach the level of "real employment" began to be put to rest early in 2001 when, within a week of her confirmation by Congress as the Secretary of the U.S. Department of Labor (DOL), Elaine Chao suggested in a speech that, "In one sense, the new economy is deconstructing work, with jobs that can't be pigeonholed into a traditional workday or workweek, and corporate structures that, in some cases, are eliminating the need for a workplace altogether. Workers themselves are demanding more autonomy, more freedom, more customization of the terms and conditions of their employment. As we invest in critical job training, we are giving workers the bargaining power they need to custom-design their jobs around their lives — instead of the other way around."

While skeptics might reasonably argue that her true intent was to weaken the power of labor unions to arbitrarily represent groups of workers, Secretary Chao's remarks, taken at face value, indicate that the strategy that had been working for people with significant disabilities for over a decade has relevance for the broader population. In other words, customized employment is real employment.

During the decade following the passage of the ADA, Congress passed sweeping reform of U.S. labor law in the Workforce Investment Act of 1998. Within this legislation, people with disabilities are welcomed into generic employment services, along with a host of other categorical groups that were consolidated within this sweeping Act. This generic system shares similar issues with employers in addressing the needs of people with disabilities. One solution identified by the U.S. Department of Labor was to use the concept of customized employment.

Even though, conceptually, customized employment represents a relevant approach for both people with disabilities and the general population, it is fair to say that little has been written or discussed about the strategy on a nationwide basis until the summer of 2001. On July 20, 2001, the Federal Register published a solicitation for projects to implement customized employment options within DOL-mandated local workforce boards for people with disabilities who might need such approaches to become successfully employed. Again this year, DOL has issued a solicitation containing the following definition of customized employment that will be used in the proposal for federal funds:

"Customized employment means individualizing the employment relationship between employees and employers in ways that meet the needs of both. It is based on an individualized determination of the strengths, needs, and interests of the person with a disability, and is also designed to meet the specific needs of the employer.

It may include employment developed through job carving, self-employment or entrepreneurial initiatives, or other job development or restructuring strategies that result in job responsibilities being customized and individually negotiated to fit the needs of individuals with a disability.

Customized employment assumes the provision of reasonable accommodations and supports necessary for the individual to perform the functions of a job that is individually negotiated and developed (Federal Register, June 26, 2002, Vol. 67. No. 123 pp 43154 -43149).

Characteristics of Customized Employment

Possibly the most defining characteristic of cstomized employment is that it is "real employment" — real employment performed in typical community work settings for typical wages by one person. Customized employment is different from other forms of employment mainly in terms of the unique manner in which the essential responsibilities (ADA, 1990) of the job are negotiated by or on behalf of an applicant and the suggestion that applicants and family members consider allowing job developers to disclose aspects of the person's disability for purposes of negotiation. Other characteristics of customized employment include:

- ❖The job description of an applicant with a disability is customized through voluntary negotiation with an employer.
- ❖Applicants with disabilities often, though not always, use job developers to assist in the negotiation of customized job descriptions.
- ❖The primary focus of the customized job description is on contribution instead of competition.
- ❖Job developers and applicants with disabilities present employers with a proposal to be considered by the employer in a voluntary manner.
- ❖Applicants voluntarily disclose issues concerning their disabilities as a good faith strategy to resolve support and accommodation issues.
- ❖Negotiation is based on a "template strategy" in which an applicant's potential contributions are placed as a template over potential employer needs. Any matches between applicant contribution and employer need might become the component responsibilities of a customized job description.
- ❖Funding for additional applicant support needs, beyond those provided by employers through reasonable accommodations and supports offered to typical employees, might be available through funding sources such as vocational rehabilitation, the workforce system, social and adult services, schools and community organizations.
- ❖While job responsibilities and the conditions of employment that surround the job

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are negotiated, pay is determined by the commensurate wage paid for the traditional job description most similar to the customized job.

The implications for individuals with significant disabilities seem clear. Customized employment offers a strategy from which all people who wish to become employed can become employed. It is our responsibility within TASH to recommit to assuring the provision of the supports, representation, resources and, most importantly, the values necessary to make employment a part of life for all.

Customized Employment for Marci Garvin

Marci is a woman from Ft. Worth, Texas, who experiences the most significant impact of disability in her life. Marci represents almost perfectly an entire group of people in our society for whom the idea of a meaningful life evokes feelings of confusion, complexity and doubt. Even if society were to embrace the notion that Marci should have a life of participation and passion, membership, relevance and the opportunity for contribution, figuring out how to assist her to accomplish this would still be difficult.

As a child of the "94-142" generation, she had access to educational services in a manner that earlier members of her group never dreamed. However, the role of school in the lives of people with the most significant disabilities is often as unclear as the role of adult services in assisting people with such labels to be active participants in our culture. The implied promise of an effective and inclusive education is that if one receives it, as a result there should be some clear benefit in relation to adult life. When Marci reached the age of 21, the path ahead seemed to lead only to an adult day center or to her family's living room. To her parents thinking, this kind of life seemed unfair, boring and unsatisfactory.

While Marci's parents were confused as to what a meaningful life should look like, they felt she needed to make a contribution to her community and be appreciated for that contribution. Some would say that Marci and people like her should simply be appreciated, honored and included in society "for whom they are," without arbitrary or typical expectations. While Marci's parents certainly agreed with the idea of acceptance for their daughter, they wanted far more. They wanted Marci to experience the daily routines, the variety, the ebb and flow of a typical life. Most particularly they wanted Marci to have a job.

But who was this young woman on the cusp of adulthood? In an effort to have that question answered for purposes of receiving adult services, her family had Marci "evaluated" by a well-known vocational evaluator. The results were devastating. Marci was described as functioning as a seven-month-old infant. If this assessment was accurate and meaningful, it was obviously a stretch to imagine that Marci might work for pay in the community. But her parents felt that this view of Marci — this comparative, competitive view — did not have any practical relevance. Instead, with assistance of a handful of supporters who were willing to take a risk, they embraced the idea of discovery.

Discovery allowed Marci's complex life to be explored rather than to be compared to others. It provided a new way of looking at her disability. And it set the foundation for customization of employment. Instead of seeing Marci's life in relation to traditional indicators of success such as skill levels, productivity, independent performance and the like, she could be viewed from the perspective of what works in her life, what moves her to be present, and what kinds of supports might she need to make a contribution. We found that instead of capturing Marci in a two-page assessment report of comparative performance that her complex life could be described in a document the size of a book. Of course, no one wanted to write a book before Marci became employed, so a ten page descriptive profile was used to capture all the information found in discovery.

Marci doesn't speak and the communication she uses is the most subtle imaginable. Since birth, her mother says that Marci has never shown emotion though facial expression. Her body is often in a state of movement and, occasionally, what appears to be agitation. Her mom says that when the external situation is pleasing and meaningful to Marci, she becomes still, attentive, and present. It provides the clearest way for Marci to express choice and preference. Marci rarely interacts in a physical manner with objects and people, but we learned that she does have some control over her right arm, which is less rigid from spasticity than her left. She often moves that arm across the front of her body in a gentle rocking motion from right to left.

The process of discovery was essential to uncover the subtle manner in which Marci expresses her feelings and reacts to the world around her. We were able to determine the environmental conditions that seemed to best fit with Marci, as well as those situations and people she seemed to prefer over others. What was missing from the equation was a way for Marci to contribute in a work place.

In reviewing her school records, it was discovered that teachers had attempted to introduce a saucer-shaped electrical switch to Marci for purposes of turning on a tape recorder for playing music. Marci seems to enjoy the effect of music and this was thought to be a functional task that might lead to other ways for her to control her environment. Hand-over-hand assistance was offered to Marci to first turn on, and then turn off, the tape player. However, that task was quickly discontinued due to what was perceived as resistance on Marci's part. After careful consideration and analysis of this activity by a dedicated support person, a flaw was discovered.

While turning on the tape player is undoubtedly a functional task for those of us who love music, turning it off is not as functionally motivating. The proposed solution involved using a 20-second telephone answering tape with music that Marci seemed to like. She would be assisted to turn the music on, and after twenty seconds the tape would stop and rewind automatically. The next assist would be to turn the music back on.

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This single idea, derived through discovery, was the basis for Marci's job using customized employment as a specialty stapler in the personnel office at the Fort Worth Star Telegram, the daily newspaper for that city. She has been working for over three years in a job in which the hours are set to meet Marci's needs. The switch that Marci turned on, initially to hear the music she liked, operates the stapler. Within a couple of months, the music was no longer needed. She receives commensurate pay for her work and assistance from a job trainer funded by the Medicaid Waiver program in her state. Since starting work, Marci has routinely made more per hour than her support personnel. During the past year, shredding of personnel documents has been added to her responsibilities. This task utilizes a sheet feeder, which Marci operates with her switch, comprised of an old ink-jet printer Velcro taped to the top of the office's auto-feed shredder.

Marci has been employed for six year at the Star Telegraph. This job cracks open the door to the possibility of Marci having a life that approximates the rhythms of those led in her community. Beyond the work place, she needs assistance to first identify and, later, participate in activities that connect her to her community. In the summer of 2001, Marci and her family agreed to participate in a self-determination pilot project in her county. Through this project Marci has begun to participate in community activities outside of work that include receiving personal shopping assistance from the manager of a Bath and Body Works store, picking up her medication at her local pharmacy and having her Ensure nutritional supplement blended in a Starbucks Frappiccino. She also has recently gotten a debit card in her name to make purchases as she shops in her community.

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Using Personal Networks to Achieve Goals as You Prepare to Leave High School

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Inclusion, especially John Butterworth, Sheila Lynch Fesko, Cynthia Zafft, and Rooshey Hasnain.

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Using Personal Networks to Achieve Goals

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Additional Institute for Community Inclusion resources on this topic

Tools for Inclusion Series

Stories of Success: Using networking and mentoring relationships in career planning for students with disabilities. (February 2001, Vol. 9, No. 1)

Networking: A consumer guide to an effective job search. (January 1999, Vol. 7, No.1)

Training Manuals

Building a Self-Determined Future For All Youth. (2001)
This manual offers an exciting approach to teaching and learning leadership and self-determination skills. It is divided into twelve curriculum units that are designed to introduce middle and high school students to a broad spectrum of leadership and self-determination skills. The guide is interactive and contains a collection of learning activities and materials that pertain to leadership.

Building Community Connections: Designing a Future That Works. (1996)
This manual serves as a curriculum for a two-day workshop designed to teach individuals with disabilities to utilize their contacts in a job search. Topics covered include: tapping the hidden job market, using networks for career development and job searches, identifying and engaging individuals, keeping in touch with people without becoming a pest, creating a mutually beneficial relationship with potential employers, dealing with disclosure, and using service providers.

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Increasing Family and Consumer Choice and Control over Transition and Employment Services through the Utilization of SSA Work Incentives

BY ELLEN CONDON

Poor post-school outcomes for students with disabilities has been a continual cause for concern for educators and policy makers since the 1980's. A 1999 report by the Office of Inspector General for the U.S. Department of Health and Human Services linked poor transition outcomes for youth with disabilities to factors such as lack of employment preparation, transition planning, and lack of services and linkages to agencies prior to high school exit. While waiting lists for adult services averaging 5 years exist nationally (Wehman, 2001), resources which could be used to enhance transition planning, linkages between schools and agencies, and employment outcomes such as Social Security work incentives, remain underutilized.

The Social Security Work Incentive Program, which allows Supplemental Security Income (SSI) recipients to set aside income and resources to fund vocational services and supports, has been in place since 1974. However, the number of individuals accessing this program nationally is minimal. According to the March 2002, quarterly report from Social Security, "SSI Disabled Recipients who Work," 1,649 PASS (Plan for Achieving Support) plans are currently active in the United States, but only 1 PASS plan is in active status for an individual under the age of 18. Ninety-seven (97) PASS plans are active for young adults ages 18-21years old. According to the Social Security Administration (SSA) in 1999, thirty-six thousand (36,000) people aged 18-24 were receiving SSI and Social Security Disability Insurance (SSDI) benefits concurrently; potentially all 36,000 were eligible for PASS plans.

While PASS plans won't solve all the needs of unserved or underserved people within the disabilities systems, they could make a significant dent in the problem. Work incentives such as PASS plans have been used successfully to bridge the gap in services for students who are exiting school and being placed on adult services waiting lists, and PASS plans have been utilized to enhance transition to employment services for students who are still in school (Condon, 2002). Additionally, money generated by a PASS plan can be leveraged to entice other agencies to come to the table and fund services to support employment for a student as a collaborative investment, where they may have been reluctant to serve as the sole financial support.

Although schools are required by law to assist families in connecting with appropriate agencies and resources as a component of Transition Planning, many school personnel have little information or experience with Social Security benefits or work incentives. Comprehensive surveys of school personnel, school administrators, adult service administrators, and adult service providers in Montana consistently identified that service personnel felt it was their responsibility to refer students and families to SSA, but seldom indicated that they had any involvement, responsibility, or experience in the actual development of an application for SSA benefits or work incentives (Vogelsberg, McGregor, Buck, & Vanek, 2002). Virginia Commonwealth University estimated that only 15% of parents learn of the SSI program through school personnel (cited by Johnson, D. 2002).

In two Model Transition Demonstration projects in Montana, funded by the U.S. Department of Education, Social Security work incentives are being incorporated into transition planning for students with labels of severe disabilities and ongoing support needs. Work incentives can be a valuable resource in transition planning for several reasons. Work incentives are proving to be one avenue for generating financial resources which can support career development and employment for students while they are in school (for students who are eligible) and as they transition to adulthood. In a PASS plan, income or resources can be sheltered and used to support employment preparation at the time the PASS is approved or, saved to purchase future employment supports, services or equipment. This incentive is a viable alternate funding source to pay for supports necessary to obtain or maintain employment for students as they graduate from high school and perhaps placed on waiting lists for adult service agencies.

> Social Security work incentives such as PASS plans can be a valuable transition resource for eligible students with disabilities during school and as they graduate.... The development of PASS plans needs to be thought of as a Needed Transition Service as schools are forming interagency linkages to support the positive outcomes for students with disabilities.

Work incentives such as PASS plans can be a source of consumer controlled funds and promote choice and control for families and students who are eligible and utilize them. PASS plans are flexible in what they fund, as long as it supports employment and is written into a plan which is approved by Social Security. PASS plans have been utilized to purchase vehicles, job development services, Vocational Evaluations (or community based alternatives such as the Vocational Profile), transportation, equipment needed to start a small business and many other items or services needed to assist someone become employed, advance employment or in the case of someone who utilizes supported employment services, maintain employment. The restrictions regarding who one can contract

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Transition and Employment Services through the Utilization of SSA Work Incentives

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with to provide services are fewer using a PASS plan than if one were using state or federal disability funds, which again increases consumer choice and control. Work incentives such as PASS can be used to bridge the gap between youth and adult life while allowing students and families to choose what they need for supports, services or equipment and whom they would like to provide these services.

Are students really eligible for PASS Plans?

In January of 2002, the amount of wages students were allowed to earn before impacting their SSI checks was increased to $1320/month or a total of $5340/ year. This incentive is referred to as the Student Earned Income Exclusion. It is unlikely that students receiving SSI benefits only will become eligible for PASS plans due to their own earnings while still considered a student. However, as soon as they graduate from school, their wages, after the first $85/month (if they only receive SSI), will begin reducing their monthly SSI check, thereby making them eligible for a PASS.

The goal for schools participating in the Montana transition demonstration grants is to graduate students with severe disabilities into paid jobs of at least 20 hours per week, customized for them through an individualized Discovery and Vocational Profile process.

In one Montana school the three graduates involved in the projects were working upon graduation but were placed on waiting lists for employment services from the state Developmental Disabilities agency. All three students require some form of ongoing supports to maintain employment. PASS plans were written for each student sheltering their wages or unearned income to pay for their needed supports. It was essential for each student's Individual Education Plan (IEP) team to organize these supports in the student's Needed Transition Services and link them to appropriate agencies that could fund and provide these services prior to gradu .tion. PASS plans were written, submitted to the PASS Cadre, and approved in advance of the student graduating, contingent upon their earnings upon graduation.

Student PASS Example #1:

When Matt turned 18, his family assisted him to apply for SSI. He was determined eligible to receive the full benefit rate of $545.00/ month. Although Matt was working part time while he was still in school, his earnings were not above $5340/year (2002 Student Earned Income Exclusion amount). Since his wages were not reducing his SSI check he would not be eligible for a PASS until he graduated and began earning over $85/month (the earned income exclusion rate). For every $2 exceeding the first $85/month gross earnings, Matt's SSI check would have been reduced by $1 if he did not have a PASS plan in place.

From Matt's high school work experiences, his team knew that he would need intermittent ongoing support to enable him to remain employed. Matt had been referred to Developmental Disabilities Services for employment supports and found to be eligible, but like many young graduates, he was put on a waiting list for these services. As part of his transition planning, Platte High School set the goal to place Matt in a paid job prior to exiting high school. If Matt was working 20 hours per week after graduation, he would be eligible for approximately $200/ month in a PASS. (The amount his SSI check would be decreased due to his wages.) The need for a PASS plan was included as a transition service need on his Individual Education Plan (IEP).

Based upon Matt's aptitude and interest in numbers, computers and his abilities to find mistakes, his PASS plan was written with the work goal: to obtain a positi on within the desk top publishing field. The plan enabled Matt to hire his family to help him get to and from work and hire a person he chose to provide the critical follow-along support for his job and receive computer tutoring to enable him to acquire skills to advance his employment. His plan was written for the period of two years.

To be eligible for a PASS, an individual must have income or resources which decrease their SSI benefits. While it is unlikely for students to have high enough earnings to decrease their SSI, due to the SEIE (Student Earned Income Exclusion) amounts, they may have unearned income which reduces their monthly SSI which, in turn, would make them eligible for PASS plans while they are still in school. Sources of unearned income which were utilized for Montana students included: Adoption Subsidies, Survivor's Benefits, and Social Security Disability Insurance, (SSDI) through a retired or disabled parent's SSA account. In these cases, PASS plans began for students as young as age 14. PASS funds were set aside for future support needs or utilized to purchase services, supports, or items necessary to achieve a current Vocational Goal.

Student Pass Example #2:

Ann was a 16 year old sophomore in high school, and she had been receiving only SSI and at the full benefit rate ($545/month in 2002). However, upon the death of her father, Ann began receiving survivor's benefits of $310/month which reduced her SSI check from $545/month to $235/month thereby making her eligible for a PASS.

Her IEP team chose to write a PASS plan which would "shelter" her unearned income. Her monthly SSI check would then remain at the 2002 Federal Benefit Rate (FBR), $545.00 month. She would then use the sheltered $290 month to support the pursuit of her vocational goal.

Ann's team began with the assumption that she could work in the community if she had a position customized to meet her support needs where she could make a contribution. They had been spending time gathering information about who Ann was, what her preferences and interests were in regards to employment, what her support needs were, what job tasks she could perform and what her particular contributions might be to an employer. They had learned that Ann had an exceptional memory for schedules and details and she very readily offered solutions to

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difficulties in juggling transportation or staffing schedules in the classroom. The team identified her vocational goal to obtain a position as a logistics coordinator.

The team chose to write the Plan ending 2 months post graduation with the assumption that they would amend the plan if the goal had changed or what she needed to purchase changed or write an extension if all remained the same. The Plan paid for Job Development, Job coaching and transportation which allowed Ann to augment services provided by the school. Upon graduation the PASS was amended to include sheltering her wages in addition to unearned income for a total of $497/month. The PASS allowed Ann to purchase a wheelchair accessible van, pay for a driver and for follow-along services to support her on her job, and set aside monies for future job coaching or development if needed.

Summary

Social Security Work Incentives such as PASS plans can be a valuable transition resource for eligible students with disabilities during school and as they graduate. Strategies to increase the utilization of PASS plans need to be incorporated into transition planning for students. The development of PASS plans needs to be thought of as a Needed Transition Service as schools are forming interagency linkages to support the positive outcomes for students with disabilities.

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Employment Strand and Sessions

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Utilizing the Discrepancy Analysis Tool to Guarantee the "Perfect" Job Match
Speaker: Jennifer Joyce

Job matching is necessary for successful employment and leads to the satisfaction of employees, employers, and funding sources. This workshop describes the process used to determine potential discrepancies and their interventions in order to facilitate the "perfect" job match.

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Workforce Investment Act and One-Stop Career Centers: Opportunities and Ongoing Challenges

By David Hoff

When it comes to employment-related services, within the disability community much attention is paid to public vocational rehabilitation and those services provided and funded by developmental disability and mental health agencies. However, over the last several years, the public employment and training services that are designed to serve anyone needing assistance in finding a job have undergone extensive changes, opening a variety of opportunities for people with disabilities.

In 1998, Congress passed the Workforce Investment Act (WIA), which replaced the Job Training Partnership Act. One of the key principles of WIA is universal access. What this means is that anyone, including people with disabilities, can receive a basic level of services from the workforce development system. Under WIA, services are accessed via One-Stop Career Centers, which operate through a network of centers in each state. Each state is required to have at least one comprehensive center in each major population area.

One-Stop System Overview

One-Stops are sometimes referred to as an agency. This is really a misnomer, since a One-Stop is not a single agency, but rather multiple agencies and partners that have come together to form the One-Stop system. The intent of the One-Stop system under WIA is to provide seamless access to multiple programs and services in one location, making it easier for job seekers and employers to use these services.

A number of federally funded programs are mandated to be partners in the One-Stop system under WIA. The only mandated disability partner is the public vocational rehabilitation (VR) system (which also includes public agencies for the blind and visually impaired). As a result, some level of VR services should be available via the One-Stop system. In some cases, the entire local VR office is located at the One-Stop Center, while in others, individual VR staff are based at the One-Stop on a full-time or part-time basis. One-Stops can go beyond the federally mandated partners and form a variety of relationships and partnerships with non-mandated public and private agencies, and many examples of this exist throughout the country.

The ability to access some services without undergoing an eligibility process, and to receive services in an integrated setting, side-by-side with the general public, are a realization of the types of opportunities for which TASH and similar organizations have long advocated.

The services available via the One-Stop system are broken into three categories: core, intensive, and training. Core services provide basic assistance in finding employment. These services tend to be fairly self-directed, or are done in group settings. Intensive services, which typically provide more one-to-one assistance than core, are intended for individuals who have not become successfully employed as a result of core services. Intensive services are provided either at the One-Stop or off-site, possibly through a contract with a service provider. Training services are intended for eligible individuals who have not become successfully employed as a result of core and intensive services, and are provided off-site. Types of training services include occupational skills training; skills upgrading; and customized training for employers. Training services are provided through Individual Training Accounts which allow an individual to choose to receive training from any approved training provider. While core services are available to anyone, you must meet eligibility requirements for intensive and training services.

The set-up of the One-Stop system varies from state-to-state and even within states. The locally driven nature of the system accounts in part for the differences between One-Stops that are often observed within a state. Local Workforce Investment Boards [LWIBs] appoint the One-Stop operator. Each LWIB is its own incorporated body, and the One-Stop system is set up based on the preferences of the LWIB. While a few less populous states have only one LWIB, most states have multiple LWIBs.

Many One-Stops are free-standing facilities. Others are located within existing public settings, such as community colleges, or government complexes. Some One-Stops use a mall-like concept, with a wide range of programs and services on-site. Others have only the core services available on-site, and act as a referral point for other services based elsewhere. Full service One-Stops have a resource library which typically has a bank of computers for developing resumes, cover letters, and conducting job searches over the internet. The resource library also usually contains publications and information on looking for a job, and papers copies of job listings from local employers. Most full service One-Stops also offer basic workshops (at no charge) on job seeking, interviewing skills, and related topics. In addition, many One-Stops have support groups for job seekers. One-Stops may have many other core services available as well.

In addition to full-service centers, many states (particularly rural ones) also have satellite centers, with more limited services. Satellite centers may be free-standing facilities, but also

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may be based in other public settings such as public libraries. In addition, many states offer some services via the internet, and the US Department of Labor also has a variety of internet tools at: www.careeronestop.org

One-Stop Career Centers go by a variety of names depending on the state. The term "One-Stop" may not even be part of the name. Some states use the same name for all centers throughout the state (for example in New Hampshire, all centers are called "New Hampshire Works"), while in other states (such as Massachusetts), the name is different in each local area.

The Opportunities and Realities of the One-Stop System

Given the variety of other service options that already exist, many people with disabilities may wonder why they should even bother investigating services from the One-Stop system. There are several reasons:

❖One-Stops can expand the array of service options available. Via the One-Stop system, a person with a disability may become aware of services and opportunities that they did not know previously existed. In particular, there may be many "non-disability specific" services available, which an individual may have previously been unaware of.

❖ One-Stops provide the opportunity to receive services in a more efficient fashion. With access to an array of services available at one location, like other One-Stop customers, people with disabilities can avoid going from place to place, having to provide the same information over and over, or needing to make numerous phone calls to get the services they need.

❖ One-Stops do not have to be an "either/or" option. Many people with disabilities are using the services of the One-Stop system in addition to other services they are already receiving.

❖ The ability to access some services without undergoing an eligibility process, and to receive services in an integrated setting, side-by-side with the general public, are a realization of the types of opportunities for which TASH and similar organizations have long advocated.

Over the last few years, through a variety of initiatives, the Institute for Community Inclusion has had the opportunity to gather information and conduct site visits with One-Stop systems throughout the United States. Based on this work, and the information gathering of other entities, it is clear that in many areas of the country, One-Stop Career Centers are operating which are truly are a major contrast to the previous employment and training services, providing customer-friendly assistance and access to a wide range of services to meet individual's employment and training needs. Many One-Stops have devoted significant time, energy and resources into building up their capacity to serve people with disabilities, and are able to respond effectively in meeting a variety of customer needs.

❖ It is clear that the key to properly serving customers with disabilities is an overall focus on quality services for all customers. It has been observed that a general emphasis by the center management on making every customer feel welcome goes a long way towards ensuring that people with disabilities receive the respect and treatment to which they are entitled.

❖ The initial interaction and intake process that occurs when an individual first enters a One-Stop is crucial. Those One-Stops that have thoroughly analyzed this process to ensure that customer needs are quickly identified and responded to, and have properly trained staff at the front desk to handle a variety of customer needs, are better able to meet the needs of people with disabilities.

❖ One-Stops are implementing a variety of universal design and learning strategies to ensure that the services they offer cover a wide range of communication needs and styles, which allows the One-Stop to meet a greater range of customer needs, and reduces the need for accommodations for specific customers and the need to disclose non-apparent disabilities.

❖ Many One-Stops have dedicated significant resources to obtaining a wide range of assistive technology to ensure that computer work stations and other One-Stop services are accessible to a wide range of people with disabilities.

❖ Public Vocational Rehabilitation is increasingly recognizing the mutual benefits that can result from participating as a partner in the One-Stop system. For instance, VR clients are often participating in various workshops offered to all One-Stop customers, rather then VR spending its resources on its own groups of people in search of employment. Also, many examples exist of VR co-funding services for a consumer with other partners. For example, VR may pay for assessment services, with WIA funds used for provision of training.

❖ Beyond public VR, the One-Stop system is building a variety of partnerships with other disability entities. In some areas, Public Mental Health agencies are increasing their level of interest and involvement in the One-Stop system with referral mechanisms and collaborative service delivery. With a few exceptions, public Developmental Disability and Mental Retardation (DD/MR) agencies have had limited involvement in the One-Stop system. However, through various demonstration projections interaction is increasing, and some Development Disability Councils are beginning to dedicate resources to enhancing the ability of One-Stops to meet the needs of their clients.

❖ Community Rehabilitation Providers (CRPs) have developed a broad range of relationships with One-Stop Career Centers. Examples include: assisting consumers they are working with to use the services of the One-Stop system as a supplement to the other services the CRP is providing; job developers using the resources of the One-Stop to identify potential employment opportunities; CRPs using the One-Stop as a satellite office with a desk at the One-Stop; co-teaching of workshops with One-Stop staff; and serving as a vendor for intensive and training services.

❖ Full- and part-time benefit planners funded by the Social Security Administration work out of many One-Stop Centers.

❖ Many One-Stops and LWIBs have developed disability committees and advisory groups to promote ongoing dialogue regarding a range of disability issues and to undertake various initiatives.

❖ Many workforce boards have significantly addressed the needs of people with disabilities

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in their planning documents and strategic planning processes.

❖ There is significant interest in the new Ticket to Work program from Social Security. A few One-Stop Career Centers and Workforce Boards have already become service providers under the Ticket program, and these numbers are expected to expand significantly. Developing the capacity to be a provider under the Ticket to Work, will certainly enhance the overall ability of One-Stops to serve people with disabilities.

❖The WIA Non-Discrimination and Equal Opportunity Regulations contain strong protections for people with disabilities. The U.S. Department of Labor is expected to expand its monitoring of enforcement of these regulations over the coming months.

❖ One of the major frustrations for people with disabilities and their families is the ability to easily access information regarding services for which they may be eligible. There is increasing recognition that One-Stops provide a framework for addressing this issue. The ideal One-Stop would be one that goes well beyond the mandates of WIA, and provides information on the full range of services that an individual may be eligible for from the array of disability agencies (such as VR, Mental Health, DD/MR) and also non-disability agencies. This would include the ability to obtain assistance regarding Social Security benefits, public health benefits (Medicare/Medicaid) and other supports (such as transportation and housing) all in one location. Although no One-Stop system has been observed that is fulfilling its complete potential in this regard, there is increasing movement by some local One-Stops, to expand their role as an information and referral point for the all the workforce development activity in the community, including those services targeted towards people with disabilities.

❖ In general, the interest of One-Stop Career Centers and workforce boards in disability issues has grown significantly over the past few years. There is an increasing recognition that people with disabilities are a major population subgroup, which One-Stops must have the ability to serve. It was particularly gratifying to the author to be at a recent meeting with a One-Stop operator who stated that people with disabilities were under-utilizing the services of the local One-Stop system, and that she wanted to take steps to address this issue. Her interest had nothing to do with any additional funding opportunities, but simply because meeting the needs of people with disabilities was seen as an important part of their fundamental mission as a One-Stop operator.

Ongoing Challenges

Such practices and developments clearly demonstrate that the One-Stop system does indeed have the interest and ability to serve individuals with disabilities in an effective manner. However, these observations are certainly not consistent across the country, or even within different areas of individual states.

While the One-Stop system has made significant progress in meeting the needs of people with disabilities, there is still much to be done. Some One-Stops continue to demonstrate a limited capacity to respond to the needs of people with disabilities, which seems usually to translate into a limited ability to respond to the needs of other customer groups as well. There are still way too many cases of people with disabilities being denied services that are universally accessible to all, not being provided proper accommodations, or being automatically referred to public VR (which is not permitted under WIA). It can be particularly frustrating, given all the attention that is being paid to this issue, if your local One-Stop is still not recognizing and responding effectively to the needs of people with disabilities. Here are some suggestions for people with disabilities, in dealing with concerns with their One-Stop system:

❖ In cases where you feel you were not treated properly at a One-Stop Career Center, or just feel that the needs of people with disabilities could be better met, you should feel free to ask to meet with the manager, or Equal Opportunity Officer. Every One-Stop is supposed to have an Equal Opportunity Officer, and contact information for this individual is supposed to be prominently displayed.

❖Another alternative is to contact the Local Workforce Investment Board, which appoints the One-Stop operator, and has oversight responsibility. LWIBs are required to regularly have public meetings, which may provide a forum for input.

❖ In advocating with One-Stops and LWIBs, do more than just complain - educate! It is rare that the needs of people with disabilities are not being met because of intentional discrimination. Instead, it is often simply lack of education and awareness regarding disability issues. Offer to assist the One-Stop and LWIB to better serve people with disabilities. Put them in contact with local resources, and the range of technical assistance entities receiving funding to assist One-Stops and LWIBs with disability issues.

❖If your state or local area is receiving funding from USDOL to enhance the capacity to serve people with disabilities, you may wish to contact the individual's involved with these initiatives to determine if there are ideas and resources available to improve the One-Stop's ability to serve people with disabilities.

❖ In cases where, despite your advocacy efforts, the One-Stop and/or LWIB is continuing to not properly meet the needs of people with disabilities, you can contact the U.S. Department of Labor's Civil Rights Center (CRC), which is responsible for ensuring that workforce development services under WIA do not discriminate. Contact information for the CRC is listed in the resource section at the end of this article.

It is important to bear in mind that given their mandate to be universally accessible, One-Stops cannot be all things to all people, and there may be cases where due to limitations on resources, One-Stops are unable to meet all of an individual's employment and training needs. No matter what though, you are entitled to be treated with dignity and respect, to have access to the core services, to be provided reasonable accommodations if needed, and to receive equal consideration for intensive and training services.

Conclusion

If you have yet to go there, visit your local One-Stop Career Center and see what it's all about. If there's room for improvement, don't be silent - advocate! WIA and One-Stops

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provide a wonderful venue to prove that integrated service delivery does indeed work, to the benefit of individuals with disabilities and society as a whole. It's important to not let this opportunity slip by.

Resources

For additional information, including details on One-Stop disability initiatives in your state, please contact the National Center on Workforce and Disability/Adult at: 1-888-886-9898 (toll free) or by e-mail: contact@onestops.info; website: www.onestops.info

For information on workforce development services for transition contact the National Collaborative on Workforce and Disabilities/Youth at: 1-877-871-0744 (toll free); e-mail: collaborative@iel.org; website: www.ncwd-youth.info

To find the location of your local One-Stop Career Center, contact America's Service Locator at: www.servicelocator.org, or by calling: 1-877-US-2JOBS

Contact information for most workforce boards can be found at the National Association of Workforce Boards website: www.nawb.org

US Department of Labor, Civil Rights Center - voice: 202-693-6502; e-mail: CivilRightsCenter@dol.gov; web site: www.dol.gov/oasam/programs/crc/crcwelcome.htm

David Hoff is the Project Coordinator for the National Center on Workforce and Disability for Adults, at the Institute for Community Inclusion, UMass Boston; Voice: 617-287-4345; TTY: 617-287-4350; e-mail: david.hoff@umb.edu

PROMISING DEVELOPMENTS IN THE ONE-STOP SYSTEM

Department of Labor Disability Dollars

Many of the promising practices and developments that have occurred within the One-Stop system are in part a result of the extensive funding the U.S. Department of Labor is dedicating to building the capacity of the One-Stop system to meet the needs of people with disabilities. States that have received funding for such purposes through various Department of Labor (DOL) grant initiatives include: Alabama, Alaska, California, Colorado, Connecticut, Florida, Hawaii, Illinois, Iowa, Indiana, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, New Hampshire, New Mexico, New York, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Dakota, Tennessee, Texas, Vermont, Virginia, Washington, West Virginia, and Wisconsin.

Some of these initiatives have funded statewide efforts while others are focused on a specific local area within a state. In addition to these efforts, each of the 10 federally funded regional Disability Business Technical Assistance Centers has received funds to work with One-Stop Centers in their region.

It is important for disability advocates to be aware of the activities that are taking place within their state to determine if there are opportunities to become involved and participate in these efforts, to ensure that such efforts are truly building the capacity of the One-Stop system to meet the needs of customers with disabilities, and to learn about promising practices that are occurring for possible replication.

In addition to these various state and regional efforts, the U.S. DOL has funded two national technical assistance centers on workforce development and disability. One of the centers is focused on issues for adults, while the other is focused on issues for youth (contact information for each of these centers can be found in the Resource listing on this page). The bottom line is that literally millions and millions of dollars are being spent to ensure that the One-Stop system can properly serve people with disabilities. The end result should be increasingly greater consistency across the country in the ability of the One-Stop system to the meet the needs of the disability community.

Opportunities for Young People Under WIA

The main focus of this article is on One-Stop Career Centers, which are mainly targeted towards adults. However, One-Stop Career Centers can also be a significant resource for young people with disabilities transitioning from school-to-adult life.

For example, in Massachusetts, One-Stop Career Centers have successfully assisted a number of transitioning students to obtain employment. There are also additional options for young people under WIA, beyond One-Stops. Local Workforce Investment Boards oversee funding for a variety of youth services, which are designed to assist young people in obtaining vocational experience. Individuals with disabilities are eligible for these youth services. In addition, the U.S. Department of Labor has been awarding funds for a variety of demonstration projects focused on youth with disabilities. For additional information, contact the National Collaborative on Workforce and Disabilities for Youth (contact information in the Resource section on this page).

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GROWING JOBS IN RURAL COMMUNITIES

BY CARY GRIFFIN

Employment development for transition age youth and adults with significant disabilities is often constrained by reactions to the alleged "job market." Even today, many job developers and employment and transition specialists are taught to review the labor market and test people with disabilities to see if they "fit" within the current economic environment. In areas of high commercial activity, this approach may work well enough to reinforce its premise, but in typical markets (and especially in depressed markets) this just labels individuals with significant disabilities as "unemployable." In rural areas (and urban, too), people get jobs through various networks of association, and by being competitive in the workplace.

Employer and Consumer Control of the Job Discovery Process

The power of networks for the job seeker cannot be overstated. Without "respected other's" representation, the job seeker is just another name on an application. In interviews, job seekers may be just another applicant, except that they also have a disability. Transition/employment specialists and job seekers alike must create networks that include people who influence those who hire.

Typically, people use references such as their former bosses or professors, but many people labeled with severe disabilities have no one of community standing representing them. If transition/employment specialists take action to become known as credible and giving members of their communities, the job development process gains the respect of employers.

One promising technique for growing jobs involves nurturing community relationships and networks by establishing Active Employment Councils (AECs) or Business Leadership Networks (BLNs). These councils meet monthly and members are required to bring at least one employment lead or "contact."

One or two consumers are asked if they have an interest in exploring employment in the "contacts" business. This contact is then called and given the name of the council member who suggested calling, and an appointment to discuss employment opportunities is made. Sometimes contacts are suppliers to the council member's business, and a natural business relationship already exists that can be leveraged into job development. Often, too, the council members find that they have jobs available in their own companies and can help minimize the red tape and other roadblocks inherent in job hunting. Because business and consumers participate in the council, employment outcomes are the absolute priority for all council activity, mutually beneficial and respectful relationships form that create a force for job development in the community.

When prospecting for Council members, begin incubating the group with a core team of strongly committed employers. School personnel might logically approach the business people on the School Board and enlist their participation.

Critical lessons are being learned through such councils that seem to have universal applicability to all communities. These include :

✔In order to create employment and act as a representative for people with disabilities, the transition/employment specialist should be well known to the business community, and should have people with disabilities actively and visibly create business and personal relationships;

✔Businesses are particularly concerned about the future of students leaving public schools, and many local Chambers of Commerce, service clubs, and city/county governments have committees studying school improvement that welcome contributing committee members and can assist with job development efforts;

✔Be careful not to overlook the public sector as an employment option. There are government jobs in large cities and in the smallest of communities. Washington State, which has a large rural population, recently announced a state government initiative to hire people with severe disabilities in public sector jobs utilizing supported employment techniques.

Employers understand their workforce and production needs much better than those of us who do not work in those businesses. Employers can assist in job restructuring and on-site training efficiently and more naturally than outside human service or school personnel who typically must learn jobs first, then teach the new worker. In numerous cases, co-workers effectively instructed new workers with disabilities in task performance, while employment specialists offered instructional support and effective teaching/supervision strategies.

Staff at the Rural Institute at the University of Montana develop and create jobs in rather remote sections of the country. Often, no formal jobs exist. The strategy is to look for products or services that are needed and either create a consumer-run enterprise or help established business expand through the use of formal partnership agreements.

Recent business start-ups include a small engine repair business, run as a sole proprietorship but located within another "fix-it shop" in Plains, Montana; a stuffed animal concession at a Nature Center in Red Lodge, Montana, (where the Nature Center receives

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GROWING JOBS IN RURAL COMMUNITIES

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10% on all sales in exchange for housing the business run by a young entrepreneur with serious disabilities), et al. The possibilities are limitless. Active Employment Councils help identify local entrepreneurs and companies willing to develop partnerships and businesses within businesses, and individual members bring priceless expertise and advice concerning local market conditions.

At the heart of these councils is Peer Marketing — having an employer influence other employers to hire individuals with disabilities. This is much more powerful and effective than human service or school representatives acting as sole job developers. Employment development benefits from creative professional rehabilitation expertise, but there is a major role to be played by having business folks work face-to-face with people with disabilities in need of employment, and with their peers in the business world.

Hiring people with disabilities is, unfortunately, still viewed as a business risk. Hearing of successful employment from business and workers with disabilities provides powerful support to employers who have not yet hired. Human service roles seem most appropriate in the context of getting these constituents together and providing technical and strategic support until a quality employment relationship has been developed.

Job Carving / Job Creation

The process of breaking down jobs into their key components and reassigning those pieces in more efficient or understandable ways is called job carving. This strategy is a creative extension of job development that results in job restructuring or job creation (i.e., typical work duties are reassigned to one or more workers or a new job is created to address efficiency needs). While full-time employment is certainly a reasonable outcome, job carving is often used with individuals in transition from school-to-work or supported employment who, for a variety of reasons (including physical disability, cyclical psychiatric illness, medical fragility, available supports, and choice) may not be in the market for full-time employment. Care must be taken not to create jobs that devalue workers with disabilities by physically separating them from other workers or by having them perform tasks that are considered bothersome, dangerous, or unpleasant.

Job carving entails analyzing work duties of specific jobs and identifying specific tasks that could be assigned to employees with severe disabilities who have a proficiency for these tasks and who want to perform these jobs. Job carving can be a useful tactic for helping individuals gain experience in paid situations, and for helping employers reach a new comfort level with employees with disabilities.

Many variables influence job carving. For instance, the marketing approach in job carving is deliberate and businesslike. Transition/employment specialists should approach potential employers as diagnosticians, ready to determine needs and offer solutions to productivity challenges. Another variable is consumer employment objectives. No job development effort can take place without a thorough understanding of the type of work that is suitable and acceptable to a particular individual.

Some examples of rural job carving include:

Clerical Assistant: Duties include photocopying, formatting and copying computer disks, answering phones, assembling documents. Hours: Monday, Wednesday, and Friday, 20 hours per week.

Mail Delivery: Duties include mail, parcel, and message delivery for rural county government offices. Hours: Monday - Friday, 12.5 hours per week.

Pet Groomer: Duties include washing dogs, general animal care. Hours: Monday - Friday, 20 hours per week.

Bank Teller Assistant: Duties include sorting documents, operating coin counter equipment, paper shredding, etc. Hours: Monday - Friday, 15 hours per week.

Taxidermist Assistant: Duties include salting hides, preparation work. Monday - Friday, 20 hours per week.

Seamstress: Duties include guiding material through computerized sewing machine, quality control, packaging, etc. Monday - Friday, 40 hours per week.

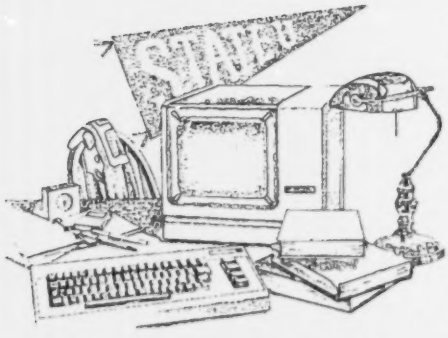
Car Wash Attendant: Duties include cleaning wash bays, refilling soap and liquid wax reservoirs, emptying vacuum cleaner bags, policing the grounds. Hours: Monday - Saturday, 22 hours per week.

Grocer's Assistant: Duties include "facing" cans on shelves, arranging produce, unloading delivery trucks, light cleaning, recycling shipping boxes. Hours: Saturday & Sunday, 16 hours per week.

Gas Station Attendant: Duties include: Pumping gasoline, washing windshields, checking oil and fluid levels, washing and detailing vehicles. Hours: Monday - Friday: 30 hours per week.

Farm Hand: Duties include: moving cattle, clearing irrigation ditches, feeding cattle, bucking bales, assorted tasks performed in partnership with the manager. Hours: 7 days per week, 35 hours per week.

Cary Griffin is Director of Special Projects, Rural Institute, University of Montana and Senior Partner, Griffin-Hammis Associates, LLC. For more information on job development, Active Employment Councils, self employment, and community employment in rural areas, please contact Cary Griffin at cgriffin@selway.umt.edu or (406) 243-2454.



INITIATIVES AT SYRACUSE UNIVERSITY PROMOTING INCLUSIVE POSTSECONDARY EDUCATION

The mission of the Center on Human Policy is to promote the full inclusion of people with disabilities. Historically, the Center has focused on issues such as deinstitutionalization, community living, education, and family support. In the past year, we have focused significant attention on inclusion in postsecondary education. This article describes two initiatives within the School of Education at Syracuse University that promote inclusion in postsecondary education. While the issues raised in these two examples are referenced to Syracuse University, they are applicable to all postsecondary educational settings.

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The Beyond Compliance Coordinating Committee (BCCC)

BY THE BEYOND COMPLIANCE COORDINATING COMMITTEE

The Beyond Compliance Coordinating Committee is a group of students at Syracuse University working to address issues of concern to people with disabilities on campus. BCCC was initiated by graduate students within the Disability Studies Concentration, within the Cultural Foundations of Education Department, School of Education, at Syracuse University. The students brought diverse backgrounds and experiences with disabilities. The commonality of the students' experiences was their commitment to creating an environment in higher education where students with disabilities would be able to thrive and reach their potential. The group quickly identified that most institutions of higher education look at accommodations for students with disabilities from a compliance mindset. It is common to hear that an institution is committed to compliance with the ADA (Americans with Disabilities Act) and other relevant laws. However, BCCC emphasizes that the ADA is simply a starting point. Mere compliance does not create an environment in which students can reach their full potential. An attitude that goes "beyond compliance" is needed within institutions of higher education. As part of their efforts, they wrote a position statement that reflects key areas of focus for an institution of higher education in order to move "beyond compliance."

The Beyond Compliance Position Statement

1. *Reshaping Syracuse University's conception of disability.*
Disability is more than just a physical or mental impairment. Accessibility is more than just compliance with federal and state laws. Disability is about the human condition, and the Syracuse University community would be enhanced by a broader conceptualization of disability that calls for inclusion, integration, and equality. Thus, compliance with laws is the starting point, not the bottom line, for the university community, and disability should be included along with race and gender in what is defined as a "minority" on campus.

2. *Raising disability consciousness on campus.*
Disability is an important aspect of diversity in a university community of scholars, faculty, and students. Inclusion of people with disabilities in the Syracuse University environment provides a learning experience for all and reaffirms the dignity of all human beings. Accordingly, disability should be part and parcel of the university's dialogue on diversity.

3. *Hiring faculty and staff members with significant disabilities.*
A pioneering university in the areas of disability studies and special education, Syracuse University should reflect its commitment to these disciplines by hiring and promoting people with significant disabilities as faculty members throughout the university.

4. *Creating model accommodations exemplifying the university's commitment to equality of opportunity for students with disabilities.*
Students with disabilities are entitled to effective reasonable accommodations and should be included in the decision-making process. Syracuse University should be committed to providing the latest in technological advances that would enhance access for students with disabilities.

For more information about BCCC, contact: Michael Schwartz, at Schwartz@twcny.rr.com

OnCampus at Syracuse University

BY VALERIE SMITH

For the past two years, a partnership between Syracuse University's School of Education and the Syracuse City School District has brought several city school students who are between the ages of 18 and 21 and who have a variety of developmental disability labels to the SU campus. These city school students audit classes, work, and socialize every day alongside their university peers. Most people can easily imagine the benefits of this arrangement to the city school students.

For example, city school participants have the opportunity to learn in classes to which they wouldn't otherwise have access, to practice social skills with same-aged peers who don't have disabilities, and to spend each day in the same environments and having similar experiences as their same-aged peers. What is equally important to recognize is that the university community, including students, staff, and faculty, also benefit from having the OnCampus students as a daily presence at Syracuse University.

Benefits to SU Community
1. OnCampus students add to the diversity at the university. They help us broaden the definition of diversity from the traditional boundaries of ethnicity, religion, and sexual orientation. They provide us with opportunities to learn the value of many kinds of diversity.

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INITIATIVES AT SYRACUSE UNIVERSITY PROMOTING INCLUSIVE POSTSECONDARY EDUCATION

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2. OnCampus students provide the campus community with opportunities to question old ideas about who belongs in higher education. They show us that, given adequate support, they are successful students, friends, and members of the university community. They cause us to examine ideas about social justice and the meaning of disability labels in society.

3. OnCampus students show us the many ways that competent people look, behave, and communicate. They help us develop skills conversing with people who don't speak, or who communicate in unique ways. They help us learn how to develop relationships with people who seem quite different from us. They help us learn that there are many important ways that we are all the same.

4. OnCampus students help faculty think differently about how, and who, they teach. OnCampus students bring the class a variety of adaptations that demonstrate innovative ways to teach all students. They make unique contributions that add to the richness of the course for all students. They demonstrate to faculty that learning, and intelligence, are expressed in many ways.

In connection with OnCampus, a service-learning course was developed. Eugene Marcus was a guest speaker in the course, sharing his experiences as a man with autism. He wrote the following in response to a question from a student about what advice he had for peer supporters of students with disabilities. Eugene now co-teaches this course.

Advice to Peer Supporters

BY EUGENE MARCUS

My friends, thank you for deciding to be supporters, and thank you for being peers and not bosses or role models. Bosses are a dime a dozen in our lives, and role models are people we choose, not ones who choose us. But peers are just what we need.

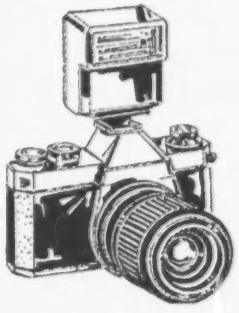
Peers are people who are in the same boat as we are, and who are our equals. That means people who must follow the same foul rules that we do, and who have ways of coping that we need to know about. Role models are expected to be perfect, but peers can fumble and make mistakes just like we do.

All we need are three things: time, respect, and information. Time is obvious, and the more the better. We mostly have way too much free time. Respect is not so observable as time, but is more important and not easy to establish if it is not there to begin with. My definition of respect is when one person assumes there is just as much chance that I am right as that he is. Good peer support is always from people who are eager to learn and that means people who don't mind being wrong a lot of the time.

The third thing our supporters provide us with is information. So what information do you peer supporters have that we need? My guess is that if you want to find out, we can tell you if you ask us. If that doesn't work, give us some choices. Real support will include lots of stories about you and your friends and your loves and your parents. And real support will help us in ways that will amaze you.

For more information on OnCampus and the service learning course contact Pat English-Sand and Eugene Marcus, 315-443-9683.

Preparation of this article was supported in part by the National Resource Center on Supported Living and Choice, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133A990001. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred. The Center subcontracts with TASH for space in the newsletter.



Through Our Lenses

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TASH is honored to have Mr. Price and several of the Through Our Lenses program participants join us at the upcoming TASH Annual Conference next month.

Mr. Price and his students will be honing their skills by photographing sessions, special events, attendees, and more throughout the conference. If you see them about, feel free to smile and say "cheese!"

Abby L. W. Crowley, EdD., is Director of Professional Development at the Lt. Joseph P. Kennedy Institute in Washington, D.C.

Questions about the Through Our Lenses program may be directed to Ms. Crowley at 202-281-2751 or by e-mail: acrowley@kennedyinstitute.org;

Photo by Ken Stein (1994).

Diane Lipton

Diane J. Lipton

(1945-2002)
Disability Rights Leader

(The following information is provided by the staff and Board of DREDF on behalf of Diane Lipton's family, Jim and Daria Armstrong and Chloe Lipton.)

Diane J Lipton, the Director of the Children with Disabilities Advocacy program at the Disability Rights Education and Defense Fund (DREDF), died in August after at the age of 57 after a two year battle with cancer.

Born in New York City, Lipton was a nationally recognized parent advocate. For nearly two decades as a lawyer fighting for the rights of children with disabilities, as well as a formidable and successful advocate for children and their parents long before she became a lawyer, Diane was a nationally recognized luminary on the front lines fighting to end disability discrimination. Diane started out her career as a teacher and rehabilitation counselor, but came to her true calling as a devoted advocate for the civil rights of children with disabilities in 1979 when her daughter Chloe, who has severe disabilities, was segregated and deprived of her educational rights as a child in the Richmond, California school system.

Diane and a few other parents, with the assistance of the Disability Rights Education and Defense Fund in Berkeley (DREDF), developed a national practice of public policy litigation and technical assistance to end the segregation of children with disabilities across the country. Her local advocacy brought about the closing of all disability-segregated schools in Richmond.

Diane and the parents she organized told the State Commission on Special Education in 1981, "Segregated education is but another form of institutionalization which we view as extremely detrimental to the growth and development of disabled and nondisabled children alike." For over twenty years, Diane never wavered from that conviction, and her professional and personal lives were seamlessly devoted to ensuring the rights of children with disabilities.

Diane's passion for justice drove her through personal sacrifices and professional struggles. She went to law school at night and joined DREDF (the Disability Rights Education and Defense Fund in Berkeley California) in 1979, where she has served as director of the State Bar Trust Fund Program and the Director of Parent and Children's Advocacy services.

Her work on state and federal legislation has had a widespread impact, from protecting the hard-earned rights of parents to participate in their children's educational plans, to ensuring the rights of children with disabilities in juvenile halls to special education.

In addition, she spearheaded a number of landmark legal cases which to this day stand out as beacons in the struggle for ensuring the rights of children with disabilities in our nation's schools. She received a number of awards and honors, including two American Jurisprudence Awards, the Distinguished Parent Award from TASH, and as well as honors and awards from the Developmental Disabilities Counsel, and the National Center in Educational Restructuring and Inclusion.

She earned a law degree from Golden Gate University School of Law, San Francisco, California, a M.S. degree in Rehabilitation Counseling from San Francisco State University and a B.A. from the University of California, Berkeley.

She is survived by her husband James Armstrong of Richmond California, and daughters Daria Armstrong (Richmond, California), and Chloe Lipton (Emeryville, California).

Diane Lipton and her family request that any donations, addressed attention: "Diane Lipton Memorial Gifts," be made to one of the following two charities:

East Bay Innovations, 440 Grand Avenue, Suite 425, Oakland, California 94610, telephone (510) 832-7126; and/or DREDF, 2212 Sixth Street, Berkeley, California 94710, telephone (510) 644-2555.

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TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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TASH CONNECTIONS

Equity, Opportunity and Inclusion for People with Disabilities since 1975

Inside This Issue

- Universal Design Holds Educational Promise
- "Enabling" Technology
- Assistive Technology Designed with the End User in Mind
- Human Centered Technology
- Section 508 and the Road to Accessibility

Opening the Doors to Technology for All People

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Cover photo by: P. Sue Kullen

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Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. **TASH** actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: **TASH**, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

TASH MISSION

TASH supports the inclusion and full participation of children and adults with disabilities in all aspects of their communities as determined by personalized visions of quality of life.

TASH's focus is on those people with disabilities who:

- Are most at risk for being excluded from the mainstream of society
- Are perceived by traditional service systems as being most challenging;
- Are most likely to have their rights abridged;
- Are most likely to be at risk for living, working, playing, and/or learning in segregated environments;
- Are least likely to have the tools and opportunities necessary to advocate on their own behalf;
- Historically have been labeled as having severe disabilities; and,
- Are most likely to need on-going, individualized supports in order to participate in inclusive communities and enjoy a quality of life similar to that available to all citizens.

TASH accomplishes this through:

- Creating opportunities for collaboration among families, self-advocates, professionals, policymakers and other advocates;
- Advocating for equity, opportunities, social justice, and rights;
- Disseminating knowledge and information;
- Supporting excellence in research that translates to excellence in practice;
- Promoting individualized, quality supports;
- Working toward the elimination of institutions, other congregate living settings, segregated schools/classrooms, sheltered work environments, and other segregated services and toward replacing these with quality, individualized, inclusive supports;
- Supporting legislation, litigation and public policy consistent with **TASH**'s mission; and,
- Promoting communities in which no one is segregated and everyone belongs.

WHOM DO I CONTACT?

- ☐ **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- ☐ **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Meetings and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- ☐ **For questions about the 2002 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- ☐ **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- ☐ **For information on governmental affairs, call:** Jamie Ruppmann, Director of Governmental Relations, at (410) 828-TASH, Ext. 104, e-mail: jruppmann@tash.org
- ☐ **For information on newsletter submissions and advertising, marketing and promotions, or permission to reprint, call:** Priscilla Newton, Director of Marketing, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- ☐ **For information on Research and Practice for Persons with Severe Disabilities (a publication of TASH), call:** Fredda Brown, Editor-in-Chief, at (718) 997-5243, e-mail: fbrowncuny@aol.com
- ☐ **Don't forget to visit TASH's web site at http://www.tash.org**

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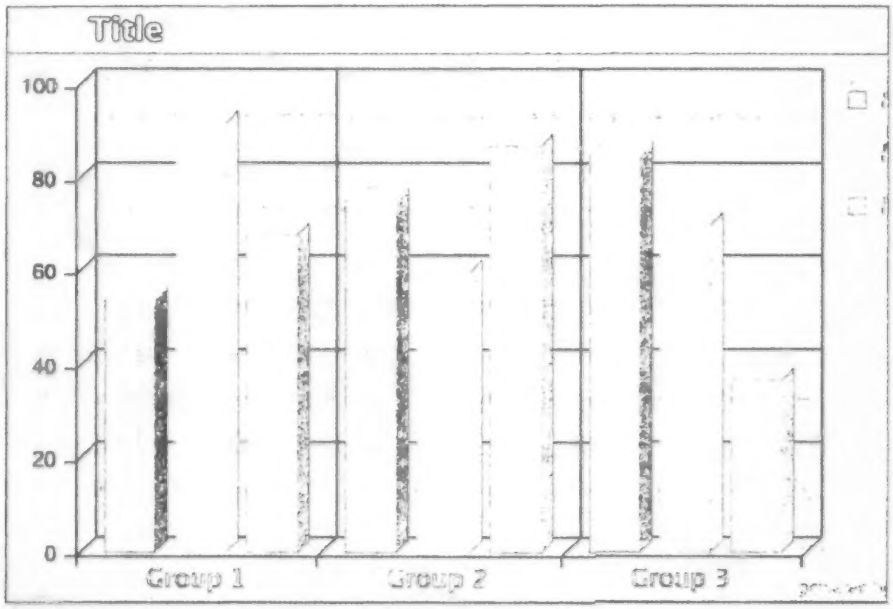
CORDA

CORDA's Interactive Visualization Programs Provide Universal Access Opportunities

As the global leader in interactive data visualization, CORDA provides equal access to information for everyone, including people who are either visually impaired or learning disabled. We are the first and only company providing multiple charting and graphing solutions that create accessible 508 compliant charts and graphs with descriptive text. Our products offer educational and career opportunities for people of all abilities.

Using our PopChart family of charting, graphing solutions and our unique descriptive text solutions, users with and without disabilities can easily and quickly build your own charts and always know where you are. Vertical bar graphs such as the one below are easy to generate with our PopChart programs. Other figures you can generate in real time appear on http://www.corda.com/examples/graph_styles/. Your non static graphs can be changed instantly as new information arrives.



d

With global accessibility as our goal, CORDA includes the descriptive text figure in all of our PopChart Solutions to facilitate the inclusion of 508 compliant charts and graphs in our entire web content. The [d] in the lower left hand corner indicates there is descriptive text available for screen readers.

Discover how you can reap the rewards from our easy to build PopChart programs by visiting www.corda.com.
Contact our sales people at sales@corda.com.
For marketing information write to Richard Lambert at rlambert@corda.com.
We are headquartered at 350 South 400 West, Suite 100, Lindon, UT 84042

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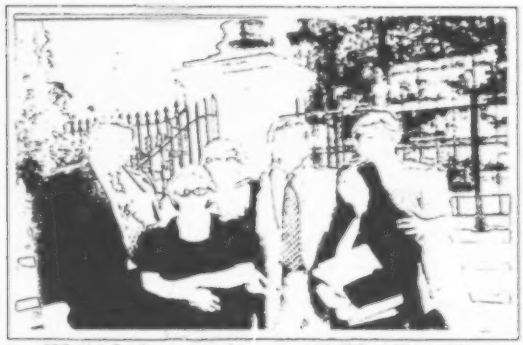
TASH: Public Policy in Action



TEAM Coalition members met with White House New Freedom Initiative staff in August to urge President Bush and the Administration to support new provisions in IDEA.

UNIVERSAL DESIGN HOLDS EDUCATIONAL PROMISE

The intent of universal design is to simplify life for everyone by making products, communications and the physical environment more usable by as many people as possible at little or no additional cost.

Just as ramps and automatic doors have made buildings more accessible, those who use wheelchairs, accommodations and modifications in instruction can make the general education curriculum more accessible to students with disabilities.

Earlier this year, TASH came together with disability rights organizations and leaders in the research and design of accessible media and technology to form the TEAM (Technology, Education and Accessible Media) Coalition.

Together, the TEAM Coalition authored and proposed amendments to the Individuals with Disabilities Education Act (IDEA) that would incorporate principles of universal design throughout IDEA and benefit students and teachers. These proposed amendments included the following:

- Children with disabilities will be able to learn more effectively and efficiently.
- Teachers and schools will save time and money by teaching all students with the same educational tools and materials.
- Fewer children are stigmatized as a result of having to obtain "special" learning materials and tools because curriculum can be presented in flexible ways that serve a wide range of student learning styles and needs.
- Students with disabilities gain knowledge working with up-to-date technologies that can help them secure employment or continue with their education.
- Students not yet identified as having disabilities benefit from a range of options to navigate, process and express information.

As a member of the Steering Committee, TASH has been assisting the TEAM Coalition's efforts. Coalition members met with all of the key staff members from the House and Senate throughout the summer and fall. The Coalition organized a briefing for Senate staff that showcased new technologies and educational materials that are "universally" designed. The Coalition will be holding another briefing in the House of Representatives this winter, and will continue to push for incorporation of principles of universal design in three primary ways:

1. Concepts of universally or exclusively designed technologies and educational material should be incorporated throughout IDEA with corresponding level of funding for research and development, and teacher training and preparation.
2. Entities that receive federal assistance should be required to ensure the accessibility of their project deliverables, including print materials, electronic media materials, web sites, videos, software, CD-ROMS and DVDs. Similarly, educational programs supported through federal assistance should be required to ensure the accessibility of their learning materials. Both of these obligations should be applied on an ongoing basis.
3. Funding for teacher training and preparation, particularly with respect to universally designed technologies and assistive technology devices, should be increased.

The Coalition will be active in the upcoming review and reauthorization of the Individuals with Disabilities Education Act, which it understands will be one of the first priorities for the incoming 108th Congress which will come into session in January 2003.

For more information about the TEAM Coalition and IDEA reauthorization contact TASH Governmental Relations Director Jamie Ruppmann at (410) 828-8274 x104 or jruppmann@tash.org.

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Family Support: The World Keeps Changing

BY CATHY FICKER TERRILL

Family support means different things to different families. The idea of family support is simply to provide families with whatever it takes for each family of children with disabilities to live as much like other families as possible. The term "family support" can mean supports, resources, services, assistive technology, financial assistance and other forms of help provided to families of children with disabilities.

The number of needs that a family has, however, should not be confused with the magnitude of any single need or the degree of its impact on a family. The needs of families are diverse and cannot be categorized into a small number of service options such as in-home or facility-based respite care. Family supports must be flexible to accommodate any family on its own terms and in ways that enable and empower the family to take control of the help it wants and needs.

The world keeps changing and family support programs need to be restructured to keep pace with family needs. Just a few short years ago we believed that the transfer of the Office of the President of the United States was an orderly process; that the Dow Jones Industrial average would easily reach 15,000; and that, with the exception of Pearl Harbor, it was inconceivable that we would ever be attacked on our own land. Who would have thought?

The future is here and the future is changing how we function. We now know that many people will live well into their 80s or longer. It is possible that we may cure all disease. There is scientific research underway to identify ways to detect genetic information about addictive behavior. You can live in a technologically interactive home where your computer responds to your personal voice commands, including a refrigerator that can order and replenish groceries through a modem so you will never have spoiled milk again. An electrode attached to an electric wheelchair can turn on lights, adjust the room thermostat, and program the oven off site. The world is changing. Diversity and technology is at the core.

Who will fund family support? It is no longer 1997, and we no longer have a budget surplus in this country. The budget deficits grow each day. How can we utilize assistive technology to do more with less? How can we enhance people's lives through empowerment with technology?

The government is able to use computer chips attached to eyeglasses with face recognition software in order to identify people. They use the technology to screen for potentially dangerous individuals in very public places. Could we modify the technology for individuals with cognitive disabilities to distinguish people in their lives they trust from strangers?

Video Buddy is an interactive and inexpensive technology for children to enhance fun and learning beginning at the preschool level. It works with a standard television and VCR. How can we work with the developers to make some simple modifications so the same technology can be available to adults with cognitive disabilities for learning in an interesting and inexpensive format? How can we get this technology into the hands of families? The basic model is available for $40.00. How can we better position families and individuals to access this and other necessary technologies?

We must use the information to change the system and enhance people's lives. We need to think strategically to get into the inner circles of research and development at Microsoft, Motorola, and all the entities that are building a better tomorrow with technology.

Technology alters the way we think and act. According to *Wired Magazine*, seven years ago in the United States, 19 million people had pagers, 12 billion voicemails were left in one year, 10 million people had fax machines, and there were 26 million new email addresses. That was seven years ago. Think how far-reaching the scope of technology must be now.

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Doctors can insert vocal implants to restore an individual's voice, or surgically implant electrodes to restore vision. Yet, I still see children and adults who don't even have a simple communication board, much less an electronic version.

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Family Support: The World Keeps Changing

Continued from page 5

Yet, there are still individuals with disabilities unable to communicate. Doctors can insert vocal implants to restore an individual's voice or surgically implant electrodes to restore vision, yet I still see children and adults who don't even have a simple communication board, much less an electronic version. We need to network outside the field of disability to work with scientists and developers to create technology for people with cognitive disabilities. Then we need to create more clearinghouses like Infinitec* to develop lease/purchase options for families to test and then acquire technology that makes a difference.

Photo by P. Sue Kullen

In the book, *The Seat of the Soul*, readers learn that, "the club that kills can drive a stake into the ground to build a shelter. The spear that takes a life can be used instead as a lever to ease life's burden, the knife that cuts flesh can be used to cut cloth, the hand that builds bombs can be used instead to build schools, and the mind that coordinates the activities of violence can coordinate the activities of cooperation." So, too, must we combine our resources to define a market of need for technology for children and adults with cognitive disabilities. We must use the information to change the system and enhance people's lives. We need to think strategically to get into the inner circles of research and development at Microsoft, Motorola, and all the entities that are building a better tomorrow with technology. We need to work with universities to develop leaders for the information age, while mentoring state funding to put technology in the hands of families of children with disabilities.

There is a visual assistant available through Ablelink Technologies in Colorado. It uses off-the-shelf hardware with custom software to provide a simple touch screen interface with voice and picture prompts to allow people to do all kinds of tasks and jobs. In fact, I refer to it as the "job coach in my pocket." It allows people to learn and have visual and oral cues in a self-paced format. The question is how can we get this technology in the hands of people with cognitive disabilities? The technology is there to accomplish all kinds of tasks, large and small, at home, at school, and at work. But we need to get access. My hope is that a working group across all the national disability organizations can come together to find solutions. We need leaders to lend their talent and capacity, their vision and new ideas to open the doors of technology to all people.

Will you help?

Cathy Ficker Terrill has been an advocate in the field of developmental disabilities for over 20 years. Cathy is the parent of a child who has a developmental disability, and works for the Ray Graham Association for People with Disabilities in Downers Grove, Illinois.

** Facilitated and managed by United Cerebral Palsy of Chicago, the Infinitec Assistive Technology Coalition permits members to share, collaborate, problem solve and create valuable and necessary assistive technology resources to better serve the mission of providing access to a quality education for all learners.*

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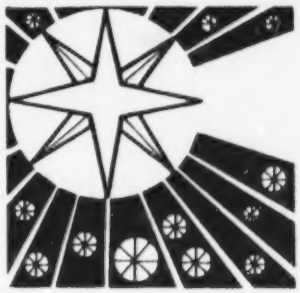

Congratulations

to the following
new and returning members of the TASH
Executive Board

Jacki Anderson (re-elected)

Ming-Gon John Lian (re-elected)

Leslie Margolis

Sue Rubin

Scott Shepard

CRUNCHY TECHNOLOGIES

Crunchy Technologies Leads in

Providing 508 Accessibility Solutions

Crunchy Technologies provides accessibility software products and software development lifecycle solutions in the public and private sectors for fast verification, correction, communication and reporting of Section 508 violations and standards. PageScreamer™ Express, PageScreamer™ , PageScreamer™ Spider, PageScreamer™ Central and WinScreamer™ provide dynamic solutions to organizations developing long-term programs enhancing accessibility for users with disabilities.

Blind, visually-impaired and individuals with learning disabilities can enhance their careers, learning opportunities and gain access to vital information through our accessible products. Federal employees with disabilities have achieved empowering authority through our products. You can too!

Knowing how education is so crucial to people with disabilities, Crunchy has partnered with George Washington University and the American Foundation for the Blind to develop comprehensive, relevant, accessible and meaningful accessible course curriculums through extensive accessibility i-learning/Training modules. Discover the value of our ***ilearning*** programs by visiting http://ilearning.crunchy.com/.

To contact us for your accessibility solutions write to: HYPERLINK "mailto:data@crunchytech.com" data@crunchytech.com. For all Customer Services related inquiries, contact 1-(877) 379-9185 or HYPERLINK "mailto:customersupport@crunchytech.com" customersupport@crunchytech.com

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Corda Reaches Out to People with Disabilities

BY NEAL WILLIAMS

Corda has long realized that people with disabilities need access to information if they want to compete educationally and professionally with people without disabilities when using computers and accessing the World Wide Web. Our access philosophy has been to provide blind, visually impaired and people with cognitive disabilities easy access to information through text-to-speech, large print and alternative color screen backgrounds. Our goal for our users is to make it as easy to use our programs as it is to cut soft butter with a steel knife. We believe in universal access to information technology for everyone because it is sound business, and it is morally right.

The Internet has over delivered on its promise to bring us information. Waves of figures, statistics, stock movements, and other data flow endlessly across our screens. While we may well be informed, we are too often overwhelmed. If sighted people with "normal" cognitive abilities feel overwhelmed, imagine the frustration of blind people and people with cognitive disabilities who must process the mountains of information. We know that when data is provided in graphic, visually appealing ways, we process it quicker with better retention.

Corda's data visualization solutions deliver dynamic interactive charts and graphs that visually display data for web sites. For six years, we have pioneered, researched and developed tools and services that help businesses, government agencies and educational institutions simplify and clarify information through intuitive, eye-pleasing visual data. An interactive graph is worth a thousand numbers because of the simplicity surrounding its interpretation. Interactive graphs can be accessible and usable by people with disabilities.

It is because we support universal accessibility for everyone that we strongly support Section 508 of the 1998 Rehabilitation Act and its benefits to people with disabilities.

Section 508 of the Rehabilitation Act

There are an estimated 800,000 people with visual disabilities currently using the Web. It is projected that there are 6.5 million Americans age 55 or older that experience severe vision loss, and by 2030 this number will double. There are an estimated 8 million people with cognitive disabilities in the United States, and we know that number will double by 2030.

On August 7, 1998, then President Bill Clinton signed into law the Workforce Investment Act of 1998. Title IV of the Act is the Rehabilitation Act Amendments, which requires that when Federal departments and agencies develop, procure, maintain, or use Electronic and Information Technology (EIT), they shall ensure that the EIT allows Federal employees with disabilities to have access to and use of information and data that is comparable to the access to and use of information and data by other Federal employees. Section 508 also requires that individuals with disabilities, who are members of the public seeking information or services from a Federal department or agency, have access to and use of information and data that is comparable to that provided to the public without disabilities. This law went into effect June 21, 2001.

To strengthen our 508 presence, Corda established a partnership with Crunchy Technologies, a provider of secure, accessible e-business and e-government software products and custom applications. Through this agreement, Crunchy has integrated Corda's Pop Chart charting and graphing solutions into Crunchy's accessible products to make web sites accessible to all members of the public.

As a result of this relationship, users can create Section 508 compliant charts and graphs with descriptive text. Crunchy's products examine the images used in web pages, and if the images contain static charts and graphs, it identifies them for the user. The user can create equivalent charts and graphs with descriptive text to meet section 508 requirements.

Descriptive text gives blind people and people with learning disabilities access to the same information contained either in a chart or graph. Crunchy's PageScreamer product will then modify the source code for the web pages to refer to the newly created charts and graphs.

Where have we had success with our descriptive text?

Providing for screen reader technology, the National Cancer Institute (NCI) has gone live with its "Cancer Mortality Maps and Graphs" Web site utilizing PopChart.com, a hosted Internet chart publishing service. The Web site, located at http://www.nci.nih.gov/atlasplus/, ranks forty different cancers for all 50 states and their 3000 counties. The NCI site allows a visitor to find and view the cancer mortality rate at the national, state or county

If you have visual disabilities, the Internet has limited usefulness. The valuable information contained in charts and graphs can't be understood unless that data is converted from graphics into text form.

We are pleased to be the first company to provide this valuable functionality so that people with visual and cognitive disabilities can have the same opportunity to utilize the potential of the Internet.

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Corda Reaches Out to People with Disabilities

Continued from page 8

level for any of the 40 cancers tracked and sorted by age, gender, time period, and ethnic background. With all of the capability of the site, there are over five million different chart and graph combinations that can be requested and viewed from the database.

Corda provided custom development for the site using its PopChart solution. The large amount of information is available for searching so that specific data can be accessed with a mouse click. "D-link" descriptive text is attached to each graph so that a person with a visual disability can understand the contents of the graph with the use of a screen reader.

"As a somewhat visually-challenged federal employee, I have a special appreciation for [descriptive text's] functionality. PopChart gives visually impaired individuals the ability to see graphs with the use of descriptive text. I am pleased that PopChart enabled the National Cancer Institute's Cancer Mortality Maps & Graphs web page to be the first at the National Institutes of Health, to be compliant with the Federal Information Technology Accessibility Initiative (Section 508)," said Dan J. Grauman, Computer Specialist at NIH.

Because of our success with Mr. Grauman, I believe the Internet is the great new hope for universal access to information and communication. Millions of pages are added each month filled with all manner of information.

We recognize that not every person with a disability has the ability to use our programs. However, we are trying to make our programs as accessible as possible. ...Our goal is universal access for all people with disabilities. We gladly welcome any input you would like to provide.

But, if you have visual disabilities, the Internet has limited usefulness. The valuable information contained in charts and graphs can't be understood unless that data is converted from graphics into text form. We are pleased to be the first company to provide this valuable functionality so that visually impaired people and people with cognitive disabilities can have the same opportunity to utilize the potential of the Internet.

I often work with charts. They are time consuming to create, and frustrating when transferring data from one document to another or from a document to the web. Since it is difficult for me to create charts, think how difficult it must be for a legally blind professional. Being legally blind in my left eye, I know the challenges people with visual disabilities face daily. For years I heard employers say, "Blind people can't use computers. They can't work with charts, they can't compete with others." Maybe that was true once, but not now. In fact, assistive technology via software is blurring the mainstream communications barriers so finely between blind workers and sighted workers that it's impossible to separate assistive technology from mainstream technology.

An example of such technology is our PopChart Xpress, an easy-to-use program that gives users the ability to produce web-ready interactive, high-quality charts and graphs quickly. PopChart Xpress is compatible with the JAWS (Job Access With Speech) screen reader. By combining the magnification feature on computers and JAWS while using PopChart Xpress, legally blind workers and people with learning disabilities can see and hear the information on charts. This combination doubles their opportunity to produce materials efficiently and independently of others.

Our program is so well designed with templates for easy usage that a novice in using charts and graphs will have little difficulty mastering the program. The template is a pre-built PopChart with a graph, legend and title box that allows you to choose a number of graph styles. The program helps users build graphs from ground zero.

You can even use PopChart Xpress to create charts for use in a PowerPoint presentation. The ease with which a user can use these charts in PowerPoint presentations strengthen the program's user value. Anyone familiar with inserting tables and graphs into documents using Microsoft Word or any other word processing program will find PopChart Xpress a joy to use. I can see the program being used by students, teachers, scientists, businesses, law enforcement, social scientists, politicians, economists – just about every profession that requires the use of charts. We recognize that not every person with a disability has the ability to use our programs. However, we are trying to make our programs as accessible as possible. To achieve this goal, we are working with the Coleman Institute on Cognitive Disabilities, Perkins Center for the Blind, Carroll Center for the Blind and the Office of Vocation Rehabilitation in Utah. Our goal is universal access for all people with disabilities. We gladly welcome any input you would like to provide.

Neal Williams is Founder and CEO of Corda Technologies, Inc. Headquartered in Lindon, Utah, Corda Technologies is a global leader in providing interactive data visualization solutions and the first company to provide a solution with D-link descriptive text for people with visual disabilities that is Section 508 compliant. With more flexibility, scalability and speed than any other charting solutions, CORDA's family of tools and services are the leading choice for fast and easy to build charts and graphs. Our solutions display data as visual images allows customers to explore relationships, perform analysis and easily understand their data.

For information on Corda's products visit www.corda.com, or send your questions to us by e-mail at rlambert@corda.com.

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Assistive Technology Is Changing the World for People with Cognitive Disabilities

BY JOHN M. WILLIAMS

Assistive technology can improve opportunities for people with disabilities. In the United States, the Coleman Institute for Cognitive Disabilities reports there are 20 million people with cognitive disabilities. Assistive technology is playing a role in providing these individuals independence, integrity and a better quality of life.

Assistive technology products are specially designed products chosen specifically to accommodate an individual's disability or multiple disabilities. These products (also known as "accessibility aids") are developed to work with a computer's operating system and software. Assistive technology (AT) can include anything from a different type of pointing device used in place of a mouse, to a system equipped with a Braille display and screen reader.

Not all users with accessibility needs require assistive technology products. Compatibility between the operating system, software, and assistive technology products is a critical component of accessible technology.

Twenty three years ago when I began writing about the benefits of assistive technology to people with disabilities, there were less than 80 companies manufacturing products for people with disabilities, and maybe five manufacturing products specifically for people with cognitive disabilities. IBM was a leader in the field, as was EdMark.

Today, scores of companies are manufacturing a variety of products for people with cognitive disabilities. These products are tailored to meet specific communications needs of people with cognitive disabilities. Often, more than one product is needed.

Assistive technology products for people with cognitive disabilities cover every disability, gender, age, and degree of cognitive disabilities. While not everyone with a cognitive disability can use assistive technology now, within the next decade it is projected that many more will be able. The numbers of people needing these products can serve to propel the market to develop the products. Families and friends of people with cognitive disabilities are demanding these products now. And once a person with a cognitive disability discovers a cause/effect relationship with technology that allows them to communicate more effectively, they want more technology. They will demand access to it.

Photo by P. Sue Kailen

Roger Jones is a user of assistive technology devices.

A variety of products exist for people with cognitive disabilities. Some of the more widely used products include:

● Screen enlargers or screen magnifiers These devices enlarge a portion of the text on the screen, increasing the legibility for some users. Some screen enlargers allow a person to zoom in and out of a particular area of the screen.

● Screen readers are software programs that verbalize, or "speak," everything on the screen, including names and descriptions of control buttons, menus, text, and punctuation. In essence, a screen reader transforms a graphic user interface (GUI) into an audio interface.

● Speech recognition systems, also called voice recognition programs, allow users to give commands and enter data using their voices rather than a mouse or keyboard. Voice recognition systems use a microphone attached to the computer that can be used to create text documents such as letters or e-mail messages, browse the Internet, and navigate among applications and menus by voice. Speech recognition systems are also used by people with language and learning disabilities who have difficulty typing or reading text.

I have worked with students with autism who have used speech recognition systems to great advantage. Speech synthesizers receive information going to the screen in the form of letters, numbers, and punctuation marks, and then "speak" it out loud. Often referred to as text-to-speech (TTS), the voice of the computer is synthesized speech, i.e. a distinctive, sometimes monotone voice that is the joining together of preprogrammed letters and words. Using speech synthesizers allows users to review their input as they type. Speech synthesizers are also used by people with language and learning disabilities, such as people who are unable to communicate verbally.

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Assistive Technology Is Changing the World for People with Cognitive Disabilities

Continued from page 10

Talking and large-print word processors are software programs that use speech synthesizers to provide auditory feedback of what is typed. Large-print word processors allow the user to view everything in large text without added screen enlargement. Individuals with learning disabilities often use these special-featured word processors to assist them with their spelling and grammar and/or to provide the auditory feedback they require to be able to write.

Some individuals with cognitive disabilities have difficulty using keyboards. Assistive technology products that these individuals have found useful include on-screen keyboard programs, which provide an image of a standard or modified keyboard on the computer screen; keyboard filters, which include cognitive typing aids such as word prediction utilities and add-on spelling checkers; touch screens with devices placed on the computer monitor (or built into it) that allow direct selection or activation of the computer by touching the screen.

These devices can benefit some users with physical disabilities because they present a more accessible target. It is easier for some people to select an option directly rather than through a mouse movement or keyboard because that movement might require greater fine motor skills than simply touching the screen to make a selection. Other people with physical disabilities might make their selections with assistive technology such as mouth sticks. Touch screens are also used by people with language and learning disabilities who find it a simpler, direct, and intuitive process than making a selection using a mouse or keyboard.

For individuals who do not use standard speech, screen review utilities make on-screen information available as synthesized speech and pairs the speech with a visual representation of a word, for example, highlighting a word as it is spoken. Screen review utilities convert the text that appears on screen into a computer voice.

There are programs specifically designed for people with learning disabilities. Some of the more popular technologies include:

- **Word prediction programs** allow the user to select a desired word from an on-screen list located in the prediction window. This list, generated by the computer, predicts words from the first one or two letters typed by the user. The word can then be selected from the list and inserted into the text by typing a number, clicking the mouse, or scanning with a switch. These programs help users increase vocabulary skills through word prompting.

- **Reading comprehension programs** focus on establishing or improving reading skills through ready-made activities, stories, exercises, or games. These programs can help users practice letter sound recognition and can increase the understanding of words by adding graphics, sound, and possibly animation.

Reading tools and learning programs include software designed to make text-based materials more accessible for people who have difficulty with reading. Options can include scanning, reformatting, navigating, or speaking text out loud. These programs help people who have difficulty seeing or manipulating conventional print materials; people who are developing new literacy skills or who are learning English as a foreign language; and people who comprehend better when they hear and see text highlighted simultaneously.

Benefits of Enabling Technologies

I have seen people with cognitive disabilities benefit in many ways from the development of assistive technologies. Using assistive technology, children once considered uneducable have been educated; adults once considered unemployable are employed; and social skills once considered unobtainable have been learned.

The future will only improve opportunities for people with cognitive disabilities. Assistive technology products are becoming mainstreamed. Families are coming to realize untold opportunities for children with disabilities. Schools are becoming more accepting of educating children with cognitive disabilities. And adults with learning disabilities are being welcomed into society.

For people requiring assistance to purchase assistive technology products many manufacturers can arrange loan payments. Medicaid will pay for some of these products provided there is a medical need for them. Insurance companies will sometimes buy technology products to help people with disabilities return to work. There are other civic groups and non-profit organizations such as the Lions Clubs, Easter Seals and United Cerebral Palsy that have have assisted people to purchase AT devices.

John Williams is an award-winning columnist specializing in writing about disability issues. He coined the phrase "Assistive Technology." For information on Assistive Technology, visit him at at 508.com or write to him at JMMAW@AOL.COM.

"The law says that I am included, but it is my friends who say, 'TD, come sit by me.'"

On June 15, 2002 my son, Troy Daniels, graduated from Northfield High School. We have traveled a long and difficult road to get here, but Troy has worked harder than anyone else, endured more than any of us, taught us more than anyone, and had more fun doing it than I, that's for sure!

Each member of his graduating class was required to write a senior speech. Troy worked for 2 months on his. He used his computer and software, which allowed him to scan for words and also used pictures to find words he wanted to use. It was the hardest thing I have ever had to watch. Troy knew what he wanted to say, and he would not stop until he had captured the exact words. After writing his speech, he than spent hours typing it into the device he uses to speak (Libby) because people cannot understand his voice.

He than had to stand before his class and deliver the speech. When it was over, I am told(parents were not allowed to attend) that there was silence in the room. Troy's lips started to tremble, he was sure that all of his classmates thought what he had said was dumb. He was wrong. Many of his classmates, boys and girls alike, were themselves moved to tears. When the applause finally started it was like thunder and it went on and on.

In Northfield, Vermont one of the speakers at graduation exercises for the class of 2002 was a young man who has Down's syndrome, who uses a wheelchair and does not use his voice to communicate. That boy is my son, Troy Daniels. He has asked that I share this story and his speech with others who work toward a day when all people can be part of one community.

We hope that you enjoy the speech and that in some small way it will help you to keep doing the work that you are doing.

Kim Daniels, Troy's mother

Troy Daniels' Senior Speech
Monday, May 13, 2002
INCLUSION IS NOT A PLACE, IT IS A FEELING

"My name is Troy Daniels, but my friends call my TD. I have Down's syndrome. Because my heart is bad, I use a wheelchair. I do not speak very good and sometimes I use Libby.

I am person with disabilities and when I say 'my friends,' I mean friends, real friends just like everyone else. I have friends. Most of you think all people have friends, but for people with disabilities friends are not always real. I want you to know why I have friends.

Not too long ago people with disabilities could not go to school with other kids, they had to go to 'special schools.' They could not have real friends; they call people like me 'retard.' That breaks my heart.

When I came to school, there is a law that says all kids go to school in the place they live. I started school right here in Northfield with all of the senior class; we were little kids together. The law says that I can come to school, but no law can make me have friends.

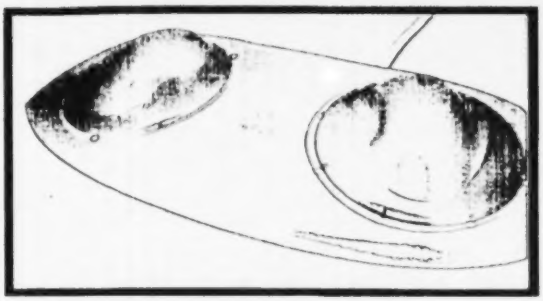
But than some kids started to think that I was okay. First, it was just one or two kids who were nice to me. They found out that I cared about them and I loved my school. I told them I want to have real friends. Others started to hang out with me and they found out we could be friends. We started to learn together that in some ways we were different, but in some ways we were the same. They called me friend and made sure that I was included in everything at school. I cared about them and they cared about me.

I want all people to know and to see that these students I call my friends are the real teachers of life. They are showing you how it should be. They are the teachers for all of you to follow their lead.

Yes, I am a person with disability. The law says that I am included, but it is my friends who say, "TD, come sit by me."

Written by Troy

Troy Daniels lives in Northfield, Vermont.



Universal Computer Access With The orbiTouch(tm) Keyless Keyboard

BY PETER McALINDON

As the information technology age advances, so must access to it by millions of people with various stages of vision impairments, and various degrees of learning disabilities, physical limitations, or both. The standard tool used to input information is a keyboard - also known as the "QWERTY."

Christopher Sholes, the inventor of the typewriter, designed the arrangement of characters on a QWERTY keyboard in 1868. His objective in designing this unique layout of keys was not user comfort or accessibility, but to avoid jamming the early mechanical typewriters.

Now fast-forward 130 years. The computer has become an ever-present tool for workers, a primary research tool or toy for others and, in many cases, an absolute necessity for people with physical and cognitive disabilities. We spend vast amounts of time using our keyboards and devices to help us work, live, play and learn. For this reason, ergonomic design, i.e. a melding of the efficiency and safety of various products and devices, has become one of the most important issues of the 1990s and into the new millennium due to the importance of computers in our technologically advanced society.

However, physical and cognitive disabilities pose challenges — sometimes impossible obstacles — to using the QWERTY and even specially designed adaptive keyboards. Because of these obstacles, people with cognitive and/or physical disabilities are left behind in the information technology field, on the job, and oftentimes in their education. Therefore, an alternative to the keyboard is required to prevent this disenfranchisement. The orbiTouch keyless keyboard is the first keyboard replacement system to go beyond mere ergonomic key layout modifications to create a truly revolutionary approach to computer interaction for every user.

Whether the person is using a computer for business, to augment communications, to surf the Web, or play a game, the means of computer interaction must be non-threatening, simple to use by people of all ages and learning and physical abilities, and standardized regardless of its size. And in the workplace, we need an approach that goes beyond standard or enhanced key-based keyboards to reduce the effects of repetitive stress injuries such as Carpal Tunnel Syndrome (CTS). An approach to computing that allows people with upper extremity disabilities the ability to type effectively and to navigate computer systems with little or no pain. To address these challenges, I created the orbiTouch, a revolutionary, fully functional 128 character keyless keyboard with an integrated mouse.

To my knowledge, the patented orbiTouch is the first alphanumeric keyboard replacement that utilizes the hands and arms, instead of the fingers, to type. Users should not have to live with hand and wrist pain. With the innovative and revolutionary design of the orbiTouch, those with disabilities now have an option that does not require fine motor movement to operate computer equipment. Keybowl, Inc.'s orbiTouch is one of the most researched keyboards designed with accessibility goals in mind.

Photo by John Williams

Dr. Peter McAlindon holds a miniaturized version of the orbiTouch.

The orbiTouch eliminates finger movement, minimizes wrist movement, and uses two ergonomically sculpted domes that are moved laterally for typing. This keyboard offers much greater flexibility in meeting the needs of its users than the common QWERTY keyboard does — even those arranged in special configurations. For the first time, anyone who types has the ability for full computer interaction; every character and mouse click is available for those for whom this may have been painful or impossible.

The orbiTouch is composed of two sculpted domes upon which the hands comfortably rest. Each dome "slides" laterally into one of eight positions from a central resting point. It is helpful to think of these dome movements moving from a central location and moving into the compass directions of N, NE, E, SE, S, SW, W, NW. Each dome is capable of sliding into the same eight compass directions.

The user creates a keystroke by sliding the two domes into one of their eight respective positions. Based on over ten years of research and multiple patents, these movements are intuitive and easy to use. With very little training, orbiTouch typists achieve adequate typing speeds very quickly. Our user tests have shown that the average computer user can be productive using the orbiTouch in three hours. However, I recognize that speed may not be the goal of a person with a significant learning or physical disability; rather, accuracy is the goal. The orbiTouch provides the user with accuracy and precision of results equivalent to pressing a key on a standard keyboard.

Ronald Davis has dyslexia and a label of autism. He was an early user of the orbiTouch and says, "It was easy to learn, and I did not make as many typing mistakes." He likes the different dome movements because of what it does for his concentration. "The movement of the domes holds my attention," says Davis. Davis has a positive attitude regarding his learning disability and sees value in assistive

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Universal Computer Access With The orbiTouch(tm) Keyless Keyboard

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technology benefiting people with cognitive disabilities. He says, "When we make technology such as the orbiTouch simple to operate, we open careers and enhance mental development for people like myself with dyslexia and autism."

The Coleman Institute for Cognitive Disabilities, Boulder, Colorado says there are 20 million people in the United States with cognitive disabilities. As Ron's experience shows, we expect that the orbiTouch will provide new opportunities for many of these individuals.

Experiences of Other Users

As we move toward the time for the broad market availability of the orbiTouch product, we have sought the reaction of potential end-users as well as professionals in healthcare, rehabilitation, and education. The comments below represent just a few of these reactions, and illustrate the guiding light that has directed our product development efforts.

The orbiTouch has international appeal. The following is a letter from a gentleman in the Netherlands:

"I am the Network Manager for a school in the Netherlands. We are interested in your keyless keyboard for our SEN (Special Educational Needs) department. ...Some of our children have difficulties with many areas of their education, one of them being the ability to type and remember where the keys are on a normal keyboard. We have done some tests with a coordination program using a mouse to type letters and they have shown a vast improvement, so your keyboard could be the answer for some of these kids."

For people with dystonia, (a neurological movement disorder characterized by involuntary muscle contractions), the orbiTouch can have significant meaning, as explained by this potential end-user:

"I am anxiously awaiting the opportunity to see if this new keyboard is the solution to my particular physical disability. I have localized dystonia which is making it increasingly difficult for me to carry out my duties as a typist/secretary. This new device may mean the difference between disability retirement (which is not appealing) and remaining a productive and efficient member of the School staff. I cannot impress upon you how important it is for me to have the opportunity to test the orbiTouch keyboard."

The orbiTouch also has appeal for a wider audience:

"I am a concerned individual who has a right hand disability to the point that my middle finger is the best for typing and my first finger is not compatible with a 'mouse' any more, but my left hand is. We have a few individuals, male and female, that are almost incapacitated because of Carpal Tunnel Syndrome, and have run into a dead end as far as their jobs go. And going on 'Leave with out Pay' has been more of a norm than would be the desire to quit or to receive disability only for two years. We need everything that relates to your product, the orbiTouch."

These are but a few of the voices of the millions of individuals for whom computer access has been only a hope, or at best a painful reality. Their requirements, combined with the perspective and guidance of professionals in every related field, have led to the development of orbiTouch.\

Using the orbiTouch

The movement of the domes to type letters is relatively simple. To type the letter "a" for example, the left dome would be moved in the "west" direction and the right dome would be moved in the "north" direction. How do you type a capital letter "A"? You move the domes the same way as typing a lower case "a" with one exception: press and hold the left dome down.

The orbiTouch does not type a character until both domes are moved into their respective positions. The domes do not have to be moved at the same time, and it does not matter which dome moves first. A slight adjustment of the spring in the domes either tightens or loosens the dome's movement. All of these features make it easier to meet the individual user's typing needs. It is important

Photo by John Williams

Kim Charlson of the Perkins Institute for the Blind works the orbiTouch with Dr. Peter McAlindon, the creator of the keyless keyboard, instructing her.

to note that the domes do not rotate when typing with the orbiTouch. In addition to making the product more difficult to use, rotating the hand and wrist in such a manner could be detrimental to the tendons and nerve through the wrist over time and may increase the likelihood of repetitive strain injury.

Availability of the orbiTouch

The orbiTouch is plug-compatible with the IBM PS2 keyboard/mouse port and standard USB ports. It may be used alone or in conjunction with a standard keyboard depending on workplace requirements. The current model works with all IBM PC compatible computers without any program or device driver modifications. Future models will be compatible with Apple computers and will also be available in handheld configurations.

The orbiTouch will be available in limited quantities in the 4th quarter of 2002, and will be generally available by in the 1st quarter of 2003. Keybowl, Inc. is establishing a network of resellers and distributors to put affordable and usable technology into the hands of the people with cognitive and or physical disabilities. Planned product availability through designated resellers and distributors is in the 1st quarter of 2003.

Additional information and online ordering may be found by visiting www.orbitouch.com.

Dr. Peter McAlindon is President, Chief Executive Officer, and Founder of Keybowl, Inc., the maker of the orbiTouch. He received his Ph.D. from the University of Central Florida in Industrial Engineering with a specialization in ergonomics.

Thank You!

TASH'S WORK IS DEPENDENT ON THE FINANCIAL ASSISTANCE OF OUR DONORS AND MEMBERS. WE WISH TO ACKNOWLEDGE THE GENEROUS DONATIONS OF THE FOLLOWING INDIVIDUALS:

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Robin Smith
Lauri Triulzi
Charlotte Vogelsang
Joe Wykowski

ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of RPSD (Research and Practice for Persons with Severe Disabilities) for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this:
Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year — in addition to an extra full year's worth of journals!

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To learn more about TASH's Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

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Human-Centered Technology: Emphasizing the A's in AT

BY ART BLASER

Several people were admiring a baby. The baby's parents accept the compliments but say, "The baby's nothing. You should see the pictures." One of my nightmares is of a crowd gathering around me. "He's nothing," someone comments, "but you should see the advanced technology."

Technology that's appropriate shouldn't obscure the person it assists. Technology can serve people or not. If the technology isn't appropriate then it's a misnomer to call it "advanced." Where application of technology enables communication, everyone benefits.

I am not a technophobe, but will argue that technology works best when it empowers humans and makes us independent. Too often it makes us dependent. Tools that should foster independence instead promote dependence and helplessness. At its best technology is truly assistive and it is appropriate.

At its best technology promotes the values expressed in the 2002 TASH Annual Conference theme: "Our Quest: Opportunity, Equality, Justice" and the TASH objectives: "Equity, Opportunity, and Inclusion for People with Disabilities."

Technological developments can aid or hinder in realizing these objectives. That's been my experience as a person with a disability. That's my professional opinion as a political scientist. We err by trying to take the politics out of disability issues. Although engineering and medicine can help, whether and how they help are political questions.

What's Technology?

Sometimes in glamorizing technology we forget what it is. It is anything or anyone helping us to do what we do. By taking such a broad view we include other humans, non-human animals, tools, and machines. It is misleading to imagine that we can be free of technology. The question is what iss most appropriate.

In writing this article I consulted several dictionaries to see how the word "technology" was defined, and I did what I often do when shopping for assistive technology. Initially, I didn't find what I wanted in the **Oxford English Dictionary**, *Cambridge English Dictionary, Funk and Wagnall's* or *Webster's*, so I kept looking until I found this, the second definition from Wordsmyth.net:

"all of the means available for dealing with practical problems in the material world."[1]

As with "environment," the question isn't whether we're for it or against it, or how much we have, but what kind. It's not whether we change, but how, why, and for whom. Changes can be good or bad, if people think about their likely effects.

About Me

At a nearby therapy pool another person said of me to a third person "I'm glad I'm not like him." I wasn't quick enough to offer a comeback, but I might have said "But you are." And we'd both have been right, because as with any two people there are similarities and differences. Usually I react to headings like the one above this paragraph by asking "Who cares?" But I'm using my example to make several points.

Technology is an important part of my life. But it's not an invitation to stop thinking. Instead, technology requires that we keep thinking, as the examples in the next paragraph illustrate.

Since 1993 I've had disabilities that affect speech, mobility, and cognition. That's when I had a brain stem stroke. I'm an avid consumer of advanced technology. I hope it promotes independence, not dependence. I've taught Political Science at Chapman University in Orange, California since 1981. Fortunately, Chapman has classrooms equipped with advanced technology. It made Yahoo's list of most "wired" colleges. I'm a nonpracticing lawyer, board member of a Center for Independent Living (the Dayle McIntosh Center in Garden Grove, California), and father (of a 4-year-old daughter, Christan, and a 1-year-old son, Marcus). Technology that's appropriate and assistive helps in all of these capacities.

Applied scientists may develop technology. But how and for whom it is used are political questions. I'm not an engineer or physician. But I'm a consumer who believes in bottom-up decision-making. Otherwise, technological developments may not "trickle down" to the grass roots.

We have to address the disability digital divide. To address it we will need to address other divides: Having a computer at home requires having a home. Having a computer at work requires having a job. Using one requires having food and medical care, and often requires having others who will explain everything. People with disabilities are on the wrong side of large gaps in all these areas. We will need to address these issues.

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Human-Centered Technology: Emphasizing the A's in AT

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About Technology I Have Used, Do Use, and/or Many People Use

I've changed choices of technology in several areas. Most changes have brought advantages as well as disadvantages. I'll discuss several examples of technology I use, or have used. Chosen forms of technology are more or less appropriate to particular individuals, circumstances, and not inherently good or bad. Adaptive aids help with everything from when I'm sleeping, to when I'm reaching for something, to when I'm watching television. I'll discuss three kinds of aids in detail: aid in writing, reading, and speaking.

Writing. Mass-marketed computer speech recognition software has improved the lives of many people with disabilities. My speech is recognized only partially, however. Newer programs have increased the part that is recognized; that part is still much less than half, however.

A human is able to do what a machine cannot, to give immediate feedback where my speech is unintelligible. Some of my writing, like this sentence, is typed very slowly, with one finger. Other parts of this essay, and much of my classroom presentations, are dictated by me, but typed by a student assistant.

These weren't the first stages in my return to writing, however. At one time I couldn't see the keyboard. Through Morse code and "amazing" technology my typing speed reached three words a minute. An "amazing" one-handed keyboard is a wonderful fit for another person's one hand but not for mine (insufficient dexterity). All of the tools I tried are useful for many other people, and may be useful for me at another time in my life. But context makes the tools I've settled on more appropriate, and the tools I've rejected less.

Reading. For about a year I didn't read printed text. This was frustrating, because I was used to reading it. Some reading material was available in an alternative format I could use, books on tape, for example. Later, I became a fan of an alternative format to hard (printed) copy, e-books.

Critics complain that e-books lack the smell and feel of "hard copies." But for someone for whom turning pages is difficult, they're a godsend. We can envision a wired e-bookstore, hard to get used to for many readers, but a source of new opportunities for many others. That opportunity is as great or as small as the proportions of written material available in e-book format, and of the population with the personal computers and internet access that e-book readers require.

Speaking. I'm a frequent user of augmentative communication: a computer will "read" a prepared text. I recently gave a presentation to my university community about war crimes tribunals. I won't engage in laborious explanations about my accompanying technological apparatus, but I can't simply let the medium be the message, lest it be the only one. Initially I'd mentioned that technological advancement (and well-equipped classrooms) made my teaching possible, and hastened to add that without it I'd likely be teaching in a very different way.

About Three A's: Assistive, Appropriate, and Automatic

What does "AT" stand for? To many readers of this article that is an easy question: assistive technology, of course. So that assistive technology doesn't become inconsistent we need to bear in mind two other meanings of AT.

The consumer is the ultimate expert. What works in the laboratory or what worked for 100 individuals in the past may not work for the 101st. Vendors and professionals provide a valuable service when they widen the menu for consumer choice. They perform a disservice when they limit consumer choice.

Similar to a good personal assistant, assistive technology is best when it empowers so that the person is noticed. It assists, it is appropriate, and it is automatic.

The web site www.Acronymfinder.com lists 68 definitions for "AT." Assistive Technology makes the list, but the top three were advanced technology, Appalachian Trail, and automatic transmission. Assistive Technology is the top of seven definitions in the Acronym Database, started on BITNET in 1991.

One term that doesn't make either list is "appropriate technology." My first encounter with the expression "appropriate technology" was in the context of political, economic, and social development. It wouldn't make sense for a country with high unemployment to import labor-saving technology. Importing a school bus, though, would likely be appropriate. For people with disabilities, some technology will be tailored to the individual and the individual's lifestyle. Other technological devices may serve the needs of the professional or vendor, but not of the person with a disability.

Perhaps the most common AT is automatic transmission. At first this meaning seemed as irrelevant to this discussion as Appalachian Trail. I'm a nondriver, but have witnessed a change from the time that many people hadn't driven a car that had automatic transmission to a time when many people haven't driven a car that doesn't have automatic transmission. There are tradeoffs, but now automatic transmission is so common that rental companies and car dealers assume that customers will want it.

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Human-Centered Technology: Emphasizing the A's in AT

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Assistive technology in the workplace should be as taken for granted as automatic transmissions on cars. Employees who do not have disabilities are assisted by technology, too. This was recognized by President Bush in his New Freedom Initiative, in also making an important distinction about the nature of the assistance provided: "As the National Council on Disability (NCD) has stated, 'for Americans without disabilities, technology makes things easier. For Americans with disabilities, technology makes things possible.'" [2] Making things possible shouldn't mean that the person with a disability becomes a person with technology. (Now if only we could eliminate the person, we could fully appreciate the technology.) Similar to a good personal assistant, AT is best when it empowers so that the person is noticed. It assists, it's appropriate, and it's automatic. It's also adaptive, alternative, and more.

Advice

People with disabilities and our allies get too much of it, but it's an irresistible impulse. So here are four suggestions for individuals.

Be skeptical. Take all advice, including mine, with a hill of salt. If you do that, you won't ignore it. That means that what worked or didn't work for me is just a report from one of the world's six billion people. My judgments were formed in a particular space and time in conditions that won't be replicated. So were the judgments of authorities and vendors.

Support Consumer Choice. The consumer is the ultimate expert. What works in the laboratory or what worked for 100 individuals in the past may not work for the 101st. Vendors and professionals provide a valuable service when they widen the menu for consumer choice. They perform a disservice when they limit consumer choice.

Be Eclectic. If something doesn't work, try something else. To find technology that fits the individual, rather than fitting the individual to the technology, will require sampling from a wide menu of choices. Choosing what works best isn't an exact science. It's a matter of trial and error and error and trial.

Moderation in Assimilation. Isn't assimilation "selling out"? Why should anyone have to assimilate? These are valid questions which I hope we'll all bear in mind.

We need to bear them in mind as we work to change perceptions. A valid response to the nightmare depicted in the second anecdote at the beginning of this essay is "That's their problem." But if it meant that social interaction was less likely and unemployment or underemployment more likely (both the conditions for people with disabilities), that's my problem, too.

Change Society

We need to address political, social, and economic barriers to technology acquisition. The cliché "The personal is political," and its converse "The political is personal," apply to all people with disabilities, including me.

We have to address the disability digital divide. To address it we will need to address other divides: Having a computer at home requires having a home. Having a computer at work requires having a job. Using one requires having food and medical care, and often requires having others who will explain everything. People with disabilities are on the wrong side of large gaps in all these areas. We will need to address these issues.

A major component of President Bush's New Freedom Initiative is assistive technology. The initiative points out huge gaps in employment and participation. If implemented alone, though, efforts to provide AT will reflect a "let them eat megabytes" philosophy.

Steps include aid to companies that encourage telecommuting, low-interest loans for AT purchase, tax-deductibility for company purchases of AT for people with disabilities to use at home, and increased investment in AT research.

My initial reaction is that the initiative has got some points in it that are okay when taken in isolation, but unfortunately things like the undermining of Social Security, the regimentation of education, and the rise in housing prices are taking place at the same time. The proposals are likely to help a few people, but I'll be surprised if the terrible numbers Bush provided have changed for the better in four or eight years.

Lots of the assistive technology is deductible for businesses anyway, and the lucky employee has a choice: Either stay in the current job or take your chances at finding an employer who understands the technology (most won't) and will get it.

I have no doubt that the New Freedom Initiative will help a few individuals and in a few years the 43d President of the United States will give a speech with great anecdotes that will obscure the figures mentioned in the New Freedom Initiative.

Technological change has beneficiaries, and will have more. Expositions of new advanced technology have beneficiaries. I'm a beneficiary and there are many people with disabilities who share my good fortune. Politics, the economy, and society should work as well for all people with disabilities as it does for us.

Art Blaser, Ph.D., J.D. is Professor of Political Science at Chapman University in Orange, California. He teaches and writes about international organizations, disability rights, and U.S. foreign policy. He has published articles in the Disability Studies Quarterly, Human Rights Quarterly, Ragged Edge Magazine, Los Angeles Times, and elsewhere. Comments on this article are welcome at <blaser@chapman.edu>

Notes

[1] <http://www.wordsmyth.net/cgi-bin/simplesearch.cgi?matchent=technology&matchtype=exact&matchid=-1&retall=1>

[2] http://www.whitehouse.gov/news/freedominitiative/freedominitiative.html

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Early Childhood Special Education

The University of Wisconsin Oshkosh College of Education and Human Services has an open position in Early Childhood Special Education (Position 111a.0203, Assistant/Associate Professor, tenure-track, academic year).

Responsibilities include teaching undergraduate and graduate courses in a collaborative program for early childhood special education and early childhood elementary education, supervision of related field experiences, professional development, research, scholarly activities, and service. A doctorate in Special Education or a related area (dissertation written prior to September 2, 2003, with a defense scheduled no later than December, 2003) is required. Prior experience teaching young children with disabilities is essential. Review of applications will begin on January 10, 2003 and continue until position is filled.

Applicants should submit a letter of application specifying position number, resume, statement of teaching philosophy, transcripts, and three current letters of recommendation to: Dr. Michael Ford, Associate Dean, College of Education and Human Services, University of Wisconsin Oshkosh, Oshkosh, WI 54901. *The University of Wisconsin Oshkosh is an Affirmative Action/Equal Opportunity Institution.*

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Crunchy's CEO talks about Section 508 and the road to accessibility

Crunchy Technologies develops 508 compliant software to ensure web content accessibility for federal employees with disabilities and for people with disabilities needing to access federal web sites. Many of these employees and individuals have learning, vision, or hearing disabilities and, in many cases, multiple disabilities. With hundreds of thousands of federal employees with disabilities, Crunchy's products benefit most federal employees with disabilities.

The following article was adapted from an interview with Crunchy Technologies' CEO, Louis Hutchinson. Reprinted with permission of iCan.com.

On June 26, 2001, Section 508 of the 1998 Rehabilitation Amendments Act became the law of the land. Section 508 states that the hardware, software and telecommunications equipment sold by vendors to the federal government must be usable by employees with disabilities. At stake are the $40 billion annual federal information technology market for vendors, and the futures of 167,000 federal employees with disabilities.

Section 508 standards apply to federal web sites, but not to privately funded web sites. Web sites or portions of Web sites provided under contract to a federal agency must also comply.

In an exclusive interview for iCan News Service, Lou Hutchinson, CEO of Crunchy Technologies, sat down with columnist John Williams and discussed the challenges the technology industry faces in assisting federal agencies in complying with Section 508.

Crunchy Technologies is one of the country's leading developers of Section 508 compliant software solutions, i.e. PageScreamer™ product line, and has been awarded numerous contracts from federal agencies to assist them in 508 compliance. Here are excerpts of that interview.

iCan: What motivated you to get involved with developing software to comply with Section 508?
Hutchinson: Crunchy was in the process of developing a workflow system where the end-user community could benefit from an accessible solution. To make sure the completed system was accessible and usable by end-users, Crunchy investigated standards for accessible development. We started developing tools to make all of our previous customer solutions accessible and usable. It was from these events and the desire to utilize technology to level the playing field that the PageScreamer™ products were developed to assist with 508 compliance.

iCan: What is the toughest challenge facing you as you develop software to assist federal agencies in complying with Section 508?
Hutchinson: Crunchy's toughest challenge usually comes from getting federal agencies to understand the magnitude of technical options afforded to them by Section 508. There are a lot of misconceptions out there, so we view this challenge as an opportunity to educate agencies, as well as vendors, on the breadth of accessible solutions for software and web content accessibility.

iCan: What does compliance mean to you?
Hutchinson: Compliance translates into a redefinition of an organization's development and management mindset. By simply seeking to retrofit web content and software applications, organizations may be selling themselves short. A retrofitting mindset should not be continually assumed. This will only lead to excessive development cost and longer inception-to-production cycles.

The ultimate goal of any Section 508 compliance endeavor should be to establish an environment where Web and software applications can be produced in accordance with the Section 508 guidelines from design inception. To facilitate this goal, developers, administrative staff, and content managers must be educated in proper coding standards and program management techniques that support accessibility guidelines.

iCan: How difficult is it for your company to develop software that complies with Section 508?
Hutchinson: Accessibility is the norm at Crunchy. From our research and development personnel to our sales associates, Crunchy staff members receive continuous training in the technical, social, management, and operational aspects of Section 508 compliance. This permits us to easily classify accessibility requirements just as we would any other user requirement. From this point, it's a measure of a company's technical ability and key process area practices. A testament to Crunchy's expertise in these areas are our numerous awards and superb client referrals for both product and service engagements.

Section 508 provides accessibility guidelines or standards for technology purchased by the federal government. ...Criticism of the standards generally occurs when companies experience difficulties in addressing the "how," [how to make their hardware, software, and telecommunications equipment accessible to both federal employees and members of the private sector wishing to utilize government web sites and other technology-oriented information systems.]

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Crunchy's CEO talks about Section 508 and the road to accessibility

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iCan: I have heard it said that Section 508 lacks standards that make it difficult for vendors to comply with Section 508. Is this true?
Hutchinson: We disagree with this statement. Section 508 provides guidelines. The "what to do," or more specifically the ruling states the functionality that is required by law to be present in all applications and Web sites. Criticism of the standards generally occurs when people experience difficulties in addressing the "how." Parent companies for technologies, such as Java and Visual Basic, were heavily involved in the structuring of Section 508, so we place great confidence in the flexibility of solutions available under the law. Vendors may be forced to think outside of the box, but in the long term this only aids the maturity of one's product or services.

iCan: When I contact federal agencies and asked them is there a single company that stands out among the best in 508 software compliance or leads, your firm always comes up in the top one to three companies. What have you done that your competitors have not?
Hutchinson: Three actions really stand out: our market entry approach, service delivery definition, and our knowledge of the federal sector. Prior to entering this market we sought expert legal counsel from Mintz Levin Cohn Ferris Glovsky and Popeo PC. This allowed us to obtain a complete understanding of Section 508, and predict the continuous evolution of the mandate by reviewing similar laws like Section 504. Our findings clearly communicated to us that a holistic approach was necessary to ensure Section 508 compliance at government agencies.

To support this belief, we pursued OEM (original equipment manufacturer) and software bundling relationships with premier software vendors, aligned ourselves with disability-related associations to increase our subject matter expertise, and designed intensive Section 508 training and application development services.

We understood from inception that the leading Section 508 solutions provider would have to provide an effective platform that supported the cultural change within federal, state & local entities in a way that enhanced these organizations immediately.

iCan: When people say there is a market out there for 508 compliance, what are we talking about in terms of federal dollars?
Hutchinson: The federal market opportunity is driven by the Section 508 law, which affects the entire supply chain. Buyers in the government cannot buy those things that they need unless the Section 508 requirements are met, which affects the supplier, which then affects other software and hardware application and commercial suppliers.

Commercial organizations are pressured to do the right thing, and are also concerned that their competitors may capitalize on the disabilities market, which is 54 million plus in the United States alone. Specifically in terms of federal dollars it has been estimated by the General Services Administration that as much as $13 billion of the $47 billion federal information technology budget in fiscal year 2002 may be spent directly or indirectly on Section 508-related initiatives.

iCan: Who are your biggest federal clients?
Hutchinson: Our biggest federal clients to date are the entire U.S. Department of Defense, the U.S. Department of Agriculture, the U.S. Department of Transportation, the Federal Communications Commission, NASA, the Consumer Products Safety Commission, the U.S. Department of the Interior, the U.S. Department of Justice, and the U.S. Department of the Treasury, to name a few. In these organizations we provide Section 508 training, testing, consulting and our PageScreamer™ products.

iCan: Do you see 508 compliance having a snowball effect among state and local governments? If yes, how are you seeing it?
Hutchinson: Yes, but in some cases it's the other way around. States like New York and Washington are well ahead in their accessibility transitions. However, most of the focus has been placed on Web content at the state and local level. As vendors publish accessible versions of their software, we will begin to see more stringent procurement guidelines, resembling those of the federal government, for state and local governments.

iCan: What do you see as short-term benefits to consumers from 508 compliance? What are the long-term benefits to consumers from 508 compliance?
Hutchinson: The most obvious short-term benefit to federal agencies is timely and cost-effective adherence to the Section 508 standards. State, local, and commercial customers gain the advantage of instantly increasing their Web site traffic, while meeting the needs of a substantial user community.

Long-term benefits are yielded from cost savings because Section 508 necessitates the use of formal coding techniques and management processes. Additionally the migration to usable Web sites and software is aided by the early transition to accessible mediums.

iCan: In your opinion, who are the lead federal agencies in 508 compliance? Who needs to catch up?
Hutchinson: The Department of Defense, the Department of Education and Social Security Administration are without a doubt the lead agencies. The accessibility advances they've made are unparalleled. Yet for all their successes and strides in the field of Web and software accessibility, they, along with others, still face challenges in meeting the Section 508 standards. Many organizations do not completely understand that creating an accessible interface means evaluating and

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Crunchy's CEO talks about Section 508 and the road to accessibility

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redefining all aspects of the technology process.

iCan: Industry always kicks and screams when government intervenes in the private market and, yet, underneath the screaming I hear, "The government is forcing us to do what we know we should do but lack the courage to do." Have you found this to be the situation with 508 compliance and do you think this situation will change?
Hutchinson: While industry is kicking and screaming, those organizations that are astute enough to realize that the cost is minimal in comparison to the return are making dramatic strides against their competition that would not have been realized without government intervention.

iCan: How many people do you have working on 508 compliant software?
Hutchinson: Everyone on our research and development team, in our consulting organization and our internal information systems organization builds only Section 508 compliant software.

iCan: What is your newest product and how is it 508 compliant?
Hutchinson: PageScreamer Spider is the enterprise version of the popular PageScreamer product, from Crunchy Technologies' suite of Web accessibility tools. PageScreamer Spider enables fast verification and automated correction of web sites that contain Section 508 violations in a single tool, plus capabilities for fast verification of Web links up to 20 levels deep. Features include:

- Verifies and corrects non-compliant Web content
- Provides a text equivalent for every non-text element
- Provides the ability to identify rows and columns in HTML tables, and much more.

iCan: Who would benefit most from using this product?
Hutchinson: PageScreamer Spider benefits technical and non-technical users who are responsible for making Web content compliant with Section 508 standards. Section 508 coordinators, Web and content developers, and information technology managers are the primary users. PageScreamer Spider has been dramatically tested internally at Crunchy Technologies and externally through outside organizations to ensure that Section 508 and usability requirements are met.

iCan: In your opinion do you believe that 508 compliance will be an ongoing task or does compliance end when a federal agency buys either hardware or software?
Hutchinson: It is in the nature of any software or hardware to evolve. This understanding alone dictates that Section 508 compliance will be an on ongoing task. Many applications are used to generate or extend other applications. Mechanisms must be put in place to ensure that these system outputs meet the Section 508 standards.

iCan: When you talk about 508 compliance training what is involved?
Hutchinson: The web development community faces numerous challenges in making Web sites compliant with the web accessibility standards defined by Section 508 of the Rehabilitation Act. In the case of new Internet, intranet, web application or extranet initiatives, developers should not assume a retrofitting mindset. Web content ought to be produced in accordance with the Section 508 guidelines from design inception. To facilitate this goal, developers and content managers must educate themselves on proper coding standards and Web accessibility techniques for specific technologies.

The goal for Section 508 is to make implementation of accessible technology solutions a transparent part of the web and application development process within organizations. This can only happen with an educational curriculum that provides an organization with the knowledge to practice ongoing standards toward Section 508 compliance.

iCan: When should accessibility training start for people interested in this field?
Hutchinson: Accessibility subjects should be discussed at the novice level and updated throughout advanced training curriculums. This is the only way to guarantee that developers, on a global level, are aware of the proper coding standards for software and Web accessibility. Accessibility training should not be positioned as an adjunct offering of regular technology courses. It must become a standard learning objective of software and Web related educational courses.
iCan: Thank you Mr. Hutchinson.
Hutchinson: You are definitely welcome.

Louis Hutchinson is CEO and Founder of Crunchy Technologies. Crunchy's approach to accessibility for people with disabilities is a universal approach. We work with people with learning disabilities as we develop new software to ensure their accessibility.

This past summer we are expanding accessibility into the education market by partnering with GWSolutions, a George Washington University Enterprise, in Washington, D.C. to integrate their eight accessibility courses into GW's Center for Professional Development Curriculum.

We believe people with any disability must have access to information on the web, and this is why we are taking the lead in 508 development.

For information on Crunchy Technologies accessibility program, send an e-mail to data@crunchytech.com.

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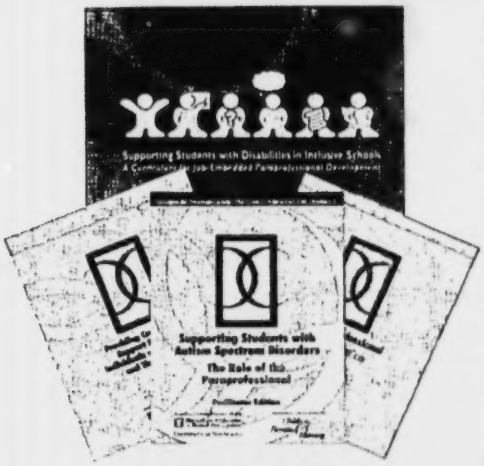
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The Role of the Paraprofessional

For Paraeducator Training and Development

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For a catalog describing the 280+ publications of the Institute on Community Integration, call 612/624-4512 or visit http://ici.umn.edu. UNIVERSITY OF MINNESOTA

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TASH NEWSLETTER

Priscilla Newton, *Editor*

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It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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